healthwatch
Wandsworth

Experiences of the Emerging Needs Pathway

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

Authors: Sarah Cook, Rhiann Isaacs, Maximilian Russel, Kayla Halls

Acknowledgements

We would like to give thanks to all individuals and organisations that were involved in this project.

We would like to extend our thanks to Healthwatch Wandsworth Volunteers Lina Abdela & Shakeel Islam for supporting us with research and analysis for this project.

We would like to extend our thanks to our colleagues at Healthwatch Merton and specifically Johan Dhinakar for assisting us with background research for this project.

Disclaimer

Please note that our findings in this report relate to observations, surveys and interviews taken from individuals and organisations and a range of articles. It should not be taken as a representative portrayal of all parents/carers, children and young people, educational professionals, and organisations that have experiences with the Emerging Needs Pathway (ENP) in Wandsworth. We spoke with 52 parents/carers who had children either currently or previously on the Emerging Needs Pathway. This must be acknowledged as a small sample size of the roughly 1,400 children currently on the Emerging Needs Pathway in Wandsworth at the time of writing.

Table of Contents

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 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), 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 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 of those we spoke to 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. Multidisciplinary Assessments

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

4. Clearer Processes and Guidelines

- We would recommend that a clear outline of the process of how to access the new 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

Official Responses to our Findings and Recommendations

NHS South West London Integrated Care Board Response:

'We are grateful to Healthwatch Wandsworth for facilitating this important piece of work. It is incredibly valuable to receive feedback from parents, carers, and professionals in shaping the new diagnostic pathway and ensuring that children and their families receive the appropriate support both before and after diagnosis.'

'The ICB has already taken action on the eight key recommendations and is working closely with the Local Authority on those that fall within their remit. For example, all parents and carers of children on the pathway have been contacted, and a dedicated enquiries email address has been created. All correspondence from parents, carers, and schools is now responded to on a weekly basis.'

St George's Hospital NHS Foundation Trust Response:

'We agree with the information contained in this report that it is reflective of people's experience of the current pathway. [The] report demonstrates that individuals spoken to were unclear on what the ENP, ICB and SGH are. New pathway needs clear information on who and how the pathway is managed.'

'We agree with the eight key recommendations and are working on these as part of our new pathway and will continue to review the recommendations to improve our service.'

Conclusion

Healthwatch Wandsworth hopes that service providers and those associated with new Social Communication Difficulties Pathway, as well as other relevant providers, will take on board our **eight key recommendations,** to ensure that the new pathway works for local people. These recommendations are based upon what we have heard from local parents/carers, SENCOs and educational professionals, and statutory and voluntary organisations, combined with background research into the national context around autism spectrum diagnosis. These recommendations align closely with the 2023 national framework and operational guidance NHS England has developed for integrate care boards in relation to delivering improved outcomes in all age autism assessment pathways.[1] We look forward to following up with relevant stakeholders after the Social Communication Difficulties Pathway is implemented to see if our recommendations have had an impact on the service user experience.

---

[1] 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/#foreword
https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#overview

1. Introduction

1.1 About Healthwatch Wandsworth

Healthwatch Wandsworth (HWW) is the patient and public champion for health and social care services. We send our reports to Healthwatch England to have an influence at a national level. HWW is funded by the Department of Health through the local authority, Wandsworth Borough Council.

Our staff and volunteers are managed by an independent local voluntary organisation, Wandsworth Care Alliance (WCA). HWW is governed by a committee consisting of Trustees of WCA members directly elected by the community.

To decide on where to focus our work we look at what people have told us when taking part in our surveys or sharing experiences with us, we speak to local health and care decision makers to hear about their plans to develop services, and we use information on local health data to set our priorities.

1.2 Identifying the project focus

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) and rename it the Social Communication Difficulties Pathway (SCD) which will be run by St George's Hospital NHS Foundation Trust (SGH). The pathway was previously redesigned in 2019; however, it was not meeting the needs of families, leading to the current redesign.

Following discussions with NHS SWL ICB, our focus was concentrated and developed around the experiences of parents/carers with 0-8 year old children on the Emerging Needs Pathway in Wandsworth. This decision was made as the topic allows us at Healthwatch Wandsworth to:

- ✓ Impact a large number of people, or have a very significant impact on a smaller number of people
- ✓ Reflect an issue raised by a large number of people

- ✓ Make a significant difference or impact
- ✓ Reflect Healthwatch priorities or the priorities and timescales of other strategic local commissioners, providers and organisations
- ✓ Highlight gaps in service delivery or the voice of local people that is not being considered
- ✓ Give voice to an issue that affects people who are less likely to be heard or highlights the experiences of excluded communities on challenging issues that may disproportionately affect people with protected characteristics, creating or perpetuating health inequalities
- ✓ Make use of our resources and capacity

2. Literature review & background research (national context)

Before carrying out our own research, multiple research articles were reviewed to better understand the current experiences and health outcomes for autistic children and their families nationally. We looked for relevant reports in academic libraries and the Healthwatch National Report Library and in total identified 40 articles, we will refer to this as the literature.

From the literature we identified 20 themes and highlighted **five primary themes** that were mentioned most frequently and their related sub themes:

Primary Theme	Sub Theme	Recommendations
• Lack of support (found in 24 articles)	• Access to tailored support • Availability of resources	• Co-production of support services • Clarity in access for support
• Long wait times (found in 17 articles)	• Effect of long wait times on the mental health of parents and children	• Interim support for those waiting for a diagnosis
• Inadequate mental health support (found in 16 articles)	• Access to good mental health support	• Offer appropriate support before crisis

• System hard to navigate (found in 15 articles)	• Clarity of the referral process	• Simplified and streamlined diagnostic pathway
• Health inequalities (found in 9 articles)	• Sex differences in rates of autism diagnosis • Ethnic differences in rates of autism diagnosis	• Better training for health and social care professionals

2.1 Lack of support

The literature shows the frustration felt by families nationally because of the lack of support provided for autistic children at every stage of the diagnostic process. People argued that support should be offered to anyone who presents a need and not just those with a diagnosis.[2] This is important especially when there are long waiting times, which we discuss later.

The literature also showed that accessing support can be difficult as parents felt that services did not work well together to meet the needs of their children.[3]

Parents expressed a lack of trust in the support that is available. Children, young people and carers report a need for person-centred, tailored support as they believe that current support is generic and ineffective.[4] Additionally, it was noted that community support is not signposted to effectively, and parents lean on each other with word-of-mouth being an important way of learning about available support.[5]

2.2 Long waiting times

Nationally, there is clear frustration around waiting times for autism diagnoses with NHS data revealing that the wait times to receive an autism diagnosis are

---

[2] Healthwatch Milton Keynes. 'Experiences of CAMHS and Mental Health support for children and young people with Special Educational Needs and Disabilities (SEND) in Milton Keynes.' Published 3 February 2022. https://www.healthwatchmiltonkeynes.co.uk/report/2022-02-03/i-am-different-not-less-experiences-camhs-and-mental-health-support-children-and

[3] Ibid.

[4] Healthwatch Croydon. 'Autism The experience of children and young people in Croydon' Published March 2016. https://nds.healthwatch.co.uk/sites/default/files/reports_library/20160301_Croydon_Autism_The_experience_of_children_and_young_people_in_Croydon_MENTAL_HEALTH.pdf

[5] Healthwatch Stockton-on-Tees. 'Views & Experiences of People Accessing or Requiring ADHD Support Services' Published January 2024. https://www.healthwatchstocktonontees.co.uk/sites/healthwatchstocktonontees.co.uk/files/Experiences%20%26%20Views%20of%20People%20Accessing%20or%20Requiring%20ADHD%20Support%20FINAL%20%28no%20data%29.pdf

long across the country.[6] Over 170,000 people were awaiting diagnosis as of December 2023, 86% of whom have been waiting longer than the recommended 13 weeks for an assessment.[7] The effects of the long waits on children and young people and their families include (but are not limited to) mental health concerns that also include self-harming and self-medicating.[8] Without a diagnosis, children, young people and their families are stuck in a holding pattern without support.

2.3 Inadequate mental health support

The literature also described how autistic people struggle to access mental health support nationally. Mental health concerns were often treated in isolation rather than holistically. For example, autistic children and young people reported being told that their mental health concerns were attributed to their autism diagnoses and were denied appropriate mental health treatment.[9]

Throughout the literature, people reported difficulty in accessing assessments and support through Child and Adolescent Mental Health Services (CAMHS) across the country. Several articles also found that, when accessed, mental health services sometimes provided a misdiagnosis and inappropriate treatment, or did not support people appropriately due to a lack of understanding around autism. [10] For example, talking therapies may not be helpful for all autistic children.[11] It was suggested that CAMHS needs an autism pathway that is specific for the needs of those with autism and other co-occurring mental health conditions.

There was also a concern around getting support for mental health in a *'timely and appropriate'* way *'Some respondents shared the feeling that their mental health was overlooked or dismissed, even when they clearly expressed a need*

---

[6] National Autistic Society. 'Autism assessment waiting times.' Published 14 March 2024. https://www.autism.org.uk/what-we-do/news/autism-assessment-waiting-times-5#:~:text=NICE%20(National%20Institute%20for%20Health,than%20the%20recommended%2013%20weeks.

[7] Healthwatch Milton Keynes. 'Experiences of CAMHS and Mental Health support for children and young people with Special Educational Needs and Disabilities (SEND) in Milton Keynes.' Published 3 February 2022. https://www.healthwatchmiltonkeynes.co.uk/report/2022-02-03/i-am-different-not-less-experiences-camhs-and-mental-health-support-children-and

[8] Ibid.

[9] Healthwatch Hertfordshire. 'Autistic People's Experiences of GP Services in Hertfordshire' Published November 2023. https://nds.healthwatch.co.uk/sites/default/files/reports_library/20231114_Hertfordshire_%20GPs%20Services%20and%20Autism%20Report%20FINAL.pdf

[10] Healthwatch Wiltshire. 'Mental health and autism: Falling between the gaps.' Published 23 October 2023. https://www.healthwatchwiltshire.co.uk/report/2023-10-23/mental-health-and-autism-falling-between-gaps#:~:text=This%20report%20highlights%20the%20findings,over%20the%20last%20three%20years

[11] Ibid.

for support'[12]. The literature suggested that nationally current support looks at response and intervention rather than prevention, meaning many autistic children are only offered support once they hit a crisis point. It suggested that inappropriate thresholds for when people can access support may add to this.

2.4 The system is difficult to navigate

In the literature people described navigating the system as *'a battle'*.[13] It showed several components that create an inconvenient system for children, young people and their carers around the UK. This includes:

- An unclear referral process
- Difficult transition periods between school ages (e.g., from the 0-8 year old autism diagnostic pathway to the 8+ autism diagnostic pathway) and from child to adult services
- Varying experiences with different providers
- Unclear information around the diagnostic process and how long this takes

> ***'I just assumed that once your child is connected with a paediatrician or an educational psychologist, they would see what you can see and carry out those the assessments that would be needed to identify your children's need'*** - Parent of an autistic teenager

2.5 Health inequalities

There are several inequalities that the literature said created further problems around autism diagnosis and support for certain groups of people nationally:

- Girls who meet criteria for ASD/C were at higher risk of not receiving a clinical diagnosis.[14]
- Children from Black and Chinese ethnic groups were more likely to be diagnosed with autism.[15]

---

[12] Healthwatch Wiltshire. 'Mental health and autism: Falling between the gaps.' Published 23 October 2023. https://www.healthwatchwiltshire.co.uk/report/2023-10-23/mental-health-and-autism-falling-between-gaps#:~:text=This%20report%20highlights%20the%20findings,over%20the%20last%20three%20years

[13] Healthwatch Sheffield. '#SpeakUp 2021 - Autism Hope.' Published 3 November 2021. https://www.healthwatchsheffield.co.uk/report/2021-11-03/speakup-2021-autism-hope

[14] What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis Loomes, Rachel et al. Journal of the American Academy of Child & Adolescent Psychiatry, Volume 56, Issue 6, 466 - 474

[15] Roman-Urrestarazu A, van Kessel R, Allison C, Matthews FE, Brayne C, Baron-Cohen S. (2021) Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. JAMA Pediatrics. 2021;175(6):e210054. doi:10.1001/jamapediatrics.2021.0054

- Children with mothers of a higher education status were more likely to have access to, and receive, a diagnosis of autism.[16]

It was reported that children have been refused an assessment on the basis that there was not enough evidence that they have a need (e.g., not exhibiting enough symptoms on the diagnostic criteria), only to re-enter the pathway later. This was the case especially for children who masked traits at school, the majority of which were girls. For some families, this went on until the child reached teenage years. This potentially indicates inappropriate thresholds that need to be met before an assessment is offered.

2.6 Literature Review Conclusions

The five primary themes we identified in our literature review showed that the issues we had heard about autism diagnosis and support in Wandsworth are not unique to the borough but are common nationally and internationally.

3. Our Findings (local context)

3.1 Survey with parents/carers of children who have sought diagnosis

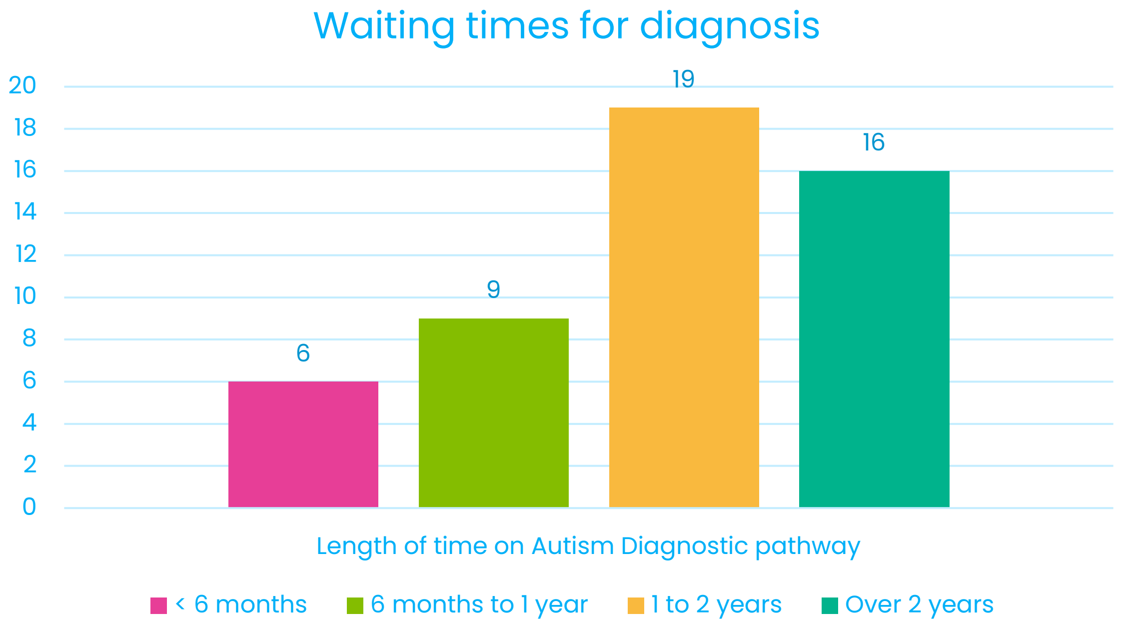
With Healthwatch Wandsworth's focus being on championing the voice of local people in relation to health and social care we knew that hearing from as many parents/carers who had an experience of the Emerging Needs Pathway was very important. In the summer of 2024, we worked to design a survey that we felt would capture the important and relevant aspects of the parent/carer experience of the Emerging Needs Pathway and also the impact on their child. With input from NHS SWL ICB and SEND Parents Carers in Wandsworth about suitable questions we distributed a survey at events and on-line via our website and other stakeholders. (You can find the complete survey in the appendix). In total from July to November 2024 we received 52 responses from parents/carers, with 29 of these having children currently on the Emerging Needs Pathway and 15 having had their child gone through the pathway. Below is a summary of themes that emerged from these responses. This must be acknowledged as a small sample size of the roughly 1,400 children currently on the Emerging Needs Pathway in Wandsworth at the time of writing.

---

[16] Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., Mason, D., & Wright, J. (2019). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8 years of age: Findings from the Born in Bradford cohort. Autism, 23(1), 131-140. https://doi.org/10.1177/1362361317733182

3.1.1 Process of getting a diagnosis

Many of our respondents noted the effect that long waiting times had on preventing their children from receiving quick support for their needs, this had a negative impact on both the child's and their family's mental health.



Waiting times: 37 out of 50 (70%) of respondents reported being on the diagnostic pathway for 1-2+ years. A smaller proportion of respondents reported being on the pathway for less than 6 months (6 out of 50, 12%) or 6 months to 1 year (9 out 50, 18%).

Additionally, it was highlighted by a parent that a secondary challenge presented by long waiting times is the risk of their child 'aging out' of the Emerging Needs Pathway for 0-8 year olds on their 8th birthday which resulted in them having to be referred to the Child and Adolescent Mental Health Service (CAMHS) autism diagnostic pathway which can potentially lengthen their waiting time.

'We waited 2 years for a face to face appointment with a Doctor at St George's where we were told he needed an autism assessment but was now too old to be assessed at St George's, he had just turned 8. We then went to CAMHS, filled all the ASD/ADHD assessment forms in but were told they were too busy to look at them, no idea when they would be able to'. – Parent of a child who was formally on the Emerging Needs Pathway

'Waiting for so long, [we] need help with the process and [are] feeling hopeless with no answer about our son's behaviour and needs.' – Parent of a child on the Emerging Needs Pathway

Communication

Alongside a desire to bring down the long waiting times, another important point mentioned by parents was the need for better communication and clarity of process. This is highlighted throughout the survey and not only applies to better communication from services to parents/carers but also between teams e.g., between occupational therapy (OT) and clinical psychology.

12 out of 38 (32%) respondents mentioned poor communication from NHS SWL ICB services while on the pathway. Respondents said the lack of communication can make them feel *'unsure of what was going on'* as they are not being updated on where their child is on the pathway.

We also asked respondents if they felt that organisations are working together. The responses were quite varied: 24% agreed they worked together; 41% disagreed; and 30% were undecided.

'It was like starting the story again [every time]. Which I think also doesn't help the speed of the process, because of this they lose time just to ask you basic questions' – Parent of a child on the Emerging Needs Pathway

'I think from last year to this year we kind of had zero news' – Parent of a child on the Emerging Needs Pathway

Customer service

A challenge reported by parents and carers was difficulty with the customer service/administrative support provided while on the diagnostic pathway. We heard that appointments were often cancelled closer to the scheduled times, and the system was described by some as *'messy'* and *'inconsiderate'*. Some parents told us about negative experiences with clinical staff. This points to an issue where parents' and carers' perception of staff as not professional or competent leads to scepticism that they will receive appropriate and relevant support for their children.

'I've sent emails and called about 30 times, all of which were unanswered. [I've] contacted people, they were telling me to contact all of them, [then they are] telling me "Can't help. Why are you contacting me?"' – Parent of a child on the Emerging Needs Pathway

'The process needs to be smoother and more cohesive. There is a lot of jumping around from service to service before being placed onto [the Emerging Needs Pathway]. Parents will need to go to see multiple different practitioners in different teams before [the

Emerging Needs Pathway] which can be confusing, and the pathway needs to be clearer. Parents should be properly signposted to relevant services.' – Parent of child on the Emerging Needs Pathway

'Be available [for parents/carers to contact], have a [public] waiting list.' – Parent of child waiting to get on the Emerging Needs Pathway

'Instil confidence by communicating effectively' - Parent of child on the Emerging Needs Pathway

'Clarity in process and waiting times. Who does what and when' - Parent of child waiting to get on the Emerging Needs Pathway

Holistic assessment of co-occurring conditions

We asked parents to give us their views on how the assessment of autism alongside other co-occurring conditions such as ADHD, anxiety, Obsessive Compulsive Disorder (OCD) etc. could be better coordinated. However, most respondents understood it as how the autism pathway could be better coordinated in general (this is the basis of Question 10 in the survey.) So, there is some overlap here.

Nevertheless, four respondents did state that they believe there should be a single pathway that addresses these multiple conditions together rather than requiring separate waiting lists and assessments.

3.1.2 Mental health impact on parents/carers

As noted earlier, most parents/carers that we spoke to have had children on the pathway for 1 to 2+ years. Parents/carers commented on the increased occurrences of feeling 'anxious', 'distressed', 'helpless' and 'hopeless' while waiting for diagnosis, and as mentioned previously, this is largely due to the difficulty in understanding certain aspects of the process such as, how to navigate the system, their status on the waitlist and appointment cancellations.

The majority (56%) of those we spoke to stated that they have not felt relaxed while their child had been on the pathway. Around 13% stated that they had felt relaxed most of the time while their child was on the pathway.

Feeling optimistic about the future was more mixed. 23% of parents/carers reported being positive overall. However, 37% stated that they never feel optimistic.

There was more positivity when parents/carers were asked if they believed that their child would get the help they need, with only 27% stating they do not think it will happen. 41% however, stated that they only have the feeling their child will get support sometimes.

Loneliness was a big issue raised by parents and carers with only 4% stating that they never feel lonely, with the majority (63%) of those we spoke to stating that they feel lonely often to always. Feelings of anxiety, sadness and being overwhelmed were also reported by the majority of those we spoke to and only 2% of parents stated that they never feel these emotions. 61% of respondents stated that they are 'almost always' or 'always' feeling anxious while being on the pathway.

These results suggest that most parents/carers do believe that their children will get help eventually and that they have hope for the future. However, the impact on mental wellbeing while on the waiting list is largely negative with feelings of anxiety and being overwhelmed common.

'It had a massive impact on us as a family. I've never been able to go back to full time work. Having him home a lot and being excluded, it's just awful, horrible. Never mind about his mental health, the whole family was struggling.' - Parent of a child who was on the Emerging Needs Pathway

'It has been two of the unhappiest years that I've had' - Parent of a child who was on the Emerging Needs Pathway

'It's really difficult to be able to combine work, often one parent is slowing down. And you know it's not something specific to Wandsworth' - Parent of a child on the Emerging Needs Pathway

3.1.3 Impact on children/young people's mental health and learning

Parents/carers noted that their children have been unable to be granted additional adjustments while at school which was having an impact on their learning and mental health. This has in turn led to social isolation and distress in both the parents/carers we spoke to and their children.

'Diagnosis took too long and came too late to make a difference to the quality of our daughter's childhood and access to suitable education provision.

Her experience of school was highly distressing, leading to severe mental crisis, Emotional Based School Non Attendance (EBSNA), Child to Parent Violence (CPV), social isolation and self-harm.

With an earlier diagnosis she could have met the admission criteria for a specialist setting. Our child was presenting with extreme distress, finding it hard to attend school, and make friends from age 6.' - Parent of a child who was previously on the Emerging Needs Pathway

3.1.4 Availability of support

It was highlighted by parents/carers that the delay in receiving a diagnosis for their children made it difficult for them to access support. However, some parents/carers have said that when they have been able to access support it has been useful:

'My son was fortunate enough at the time, he was attending Summer Nursery for Early Years. They helped us navigate a system which can be overwhelming for parents who are grappling with the needs of their child' - Parent of a child who was on the Emerging Needs Pathway

'We have been lucky as we have accessed EHCP and resource base placement without diagnosis' - Parent of a child on the Emerging Needs Pathway

This highlights a need for more services that support families without an autism diagnosis as it can be useful for helping to solve some of the difficulties reported by parents/carers with children waiting for a diagnosis.

Parents/carers were also asked if they had received information about autism and support services and who it had come from. While multiple different organisations such as Wandsworth Autism Advisory Service (WAAS) and NHS SWL ICB were acknowledged, there was no consistent source of information for parents seeking guidance highlighted by the majority of respondents we spoke to.

WAAS was mentioned by roughly 48% of respondents, being the organisation mentioned by the most respondents. Due to WAAS having a universal offer for parents with or without a diagnosis there is a line of reasoning that this should be higher. Education settings followed as the second highest acknowledged at 37.5%, followed by local authority services (excluding WAAS) at 29% and NHS SWL ICB services at 27%. 12.5% also stated that they had not received information from any services while 6% stated they were unsure if they had received appropriate information.

We also asked about how information about autism and support services could be improved. There were a range of things parents/carers thought could be improved regarding the distribution of information. The most common themes raised by parents and carers were:

- The need for better communication between services involved to provide better signposting and non-conflicting information.
- The desire for a single point of access that provides all relevant information was raised by eight respondents. While some called for this to be online, three people did state that they prefer physical pamphlets etc. as they felt it is not easy to navigate the internet. However potentially providing a single website/directory could mitigate this.
- The use of simple language and reducing medical jargon for information presented to parents/carers was also mentioned by four respondents.
- Four respondents also highlighted the need for more frequent communication from service providers and stated that email would be the best form for providing this.

A different theme raised by three respondents was that they felt that there was too much effort going into pamphlets etc. for parents and that these resources would be better used by having professionals train parents through workshops etc. to support their children themselves.

'Can there be one website with the information on it please, and an easy to understand way to contact different organisations. It is overwhelming' - Parent of a child on the Emerging Needs Pathway

'Not everyone can navigate using the internet correctly. Would also be beneficial to have support services listed in one leaflet too.' - Parent of a child who was on the Emerging Needs Pathway

'The information shared about Autism should be digestible, simple to understand, and relatable.' - Parent of a child who was on the Emerging Needs Pathway

'I just feel like it should be communicated properly because there is a lot going on and people cannot access it.' - Parent of a child on the Emerging Needs Pathway

'There should be clear articulation of the pathway, how it works & how services link together'- Parent of a child on the Emerging Needs Pathway

We also asked parents and carers about what support services they had accessed for their children. The main service mentioned by 71.7% was speech and language therapy, followed by occupational therapy (43.5%). This is promising as these services are needs-based and accessible to all children who are referred, regardless of diagnosis status. These NHS SWL ICB services work closely with WAAS so there is hope that if more parents are aware of these services they would access them.

We also followed up by asking what specific services have been useful for parents for their children. This varied from peer-led groups to voluntary organisations and statutory organisations all being mentioned.

3.2 Survey with Special Educational Needs Coordinators (SENCOs)

Having heard from various stakeholders the importance of educational professionals in relation to parents/carers in the process of seeking a diagnosis for their child we designed a survey to gain insights from Special Educational Needs Coordinators (SENCOs). This survey was sent in October 2024 to SENCOs via Wandsworth Borough's Children's Services department. We received 10 responses, seven of which were from SENCOs and three which were from other educational professionals all coming from primary school settings. This must be acknowledged as a very small sample size and therefore should not be taken to represent the views or experiences of all educational professionals in Wandsworth.

3.2.2 Process of getting a diagnosis

All the respondents reported wait times for diagnosis of 1-2+ years with most (60%) reporting children being on the waiting list for over two years. This is similar to the experiences reported by parents/carers in our other survey.

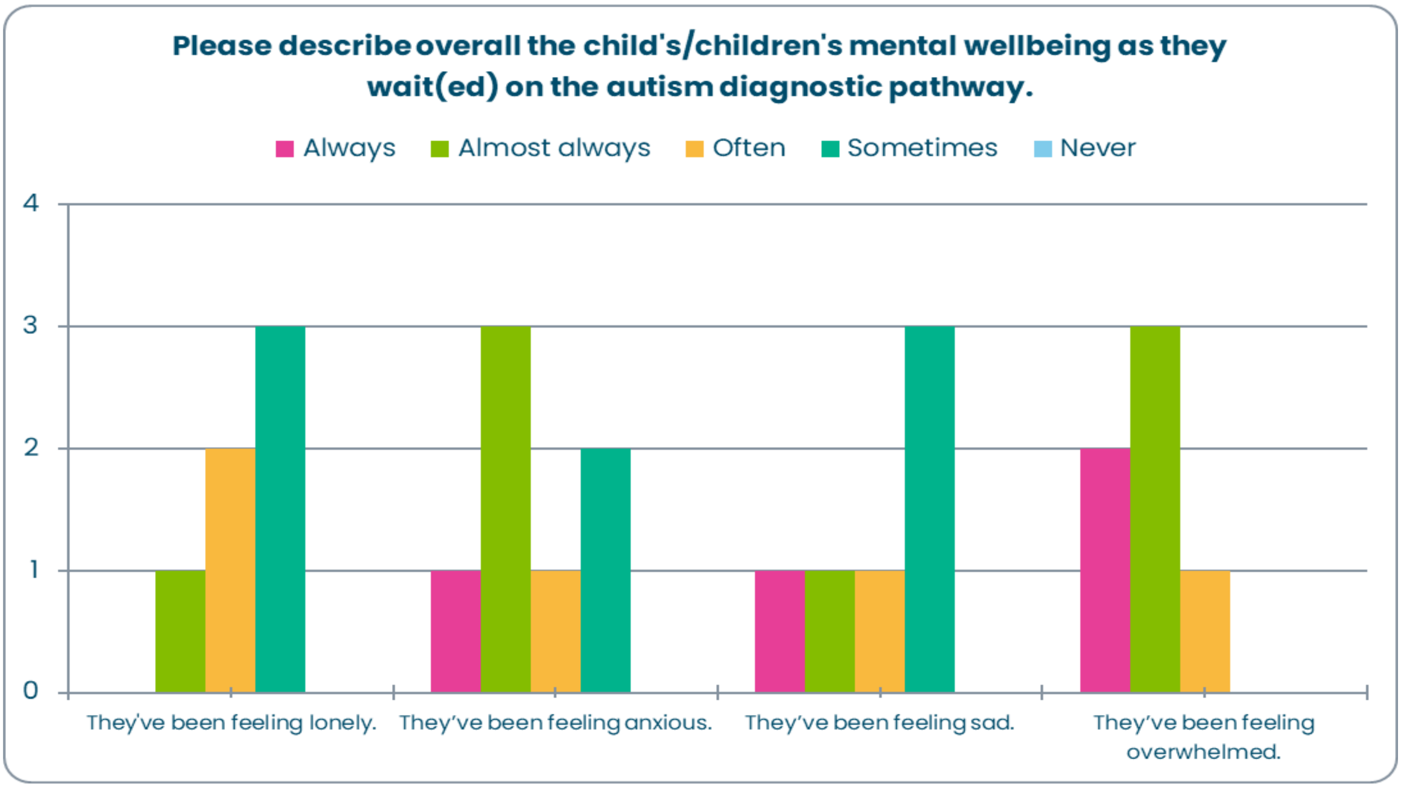
When asked about the overall experience of trying to get a diagnosis for a child on the Emerging Needs Pathway, 60% of respondents described it as 'very poor' with 40% describing it as either 'poor' or 'okay'.

The poor view of the Emerging Needs Pathway for 0–8 year-olds by educational professionals reflected concerns shared around a multitude of issues with the pathway including: lack of resources (e.g., they told us that they thought there was a lack of appropriate health care professionals employed by NHS SWL ICB), confusion surrounding wait times and the diagnostic process, lack of communication (e.g., patients not being aware that they are on the waiting list because they have not been contacted), and the impact that waiting has on families' mental wellbeing.

'I think parents are often unsure of what the assessment will involve, who the appointment is with, and what the appointments they are being given [will] involve.' - SENCO

3.2.3 Mental health impact on children

Educational professionals reported feelings of loneliness, anxiety, sadness and being overwhelmed in children they interact with who are on the Emerging Needs Pathway. They also reported that children under eight, particularly non-verbal children, are generally not aware that they are waiting for an autism assessment. This suggests that for some children their mental wellbeing may not be directly impacted by how long they have been on the pathway. However, it was highlighted by a respondent that although children may not be aware that they are on the pathway, they often feel overwhelmed in school which negatively affects their mental wellbeing. This is an important observation and allows us to consider that although a child on the pathway may not be aware of how long they have been waiting for a diagnosis, the longer that they are without a diagnosis or appropriate support, the greater impact this has on their mental wellbeing.



'It is very stressful for families as they feel in limbo and powerless. It can also affect the child accessing the appropriate school if a diagnosis is required.' – Educational Professional

3.2.4 Mental health impact on parents/carers

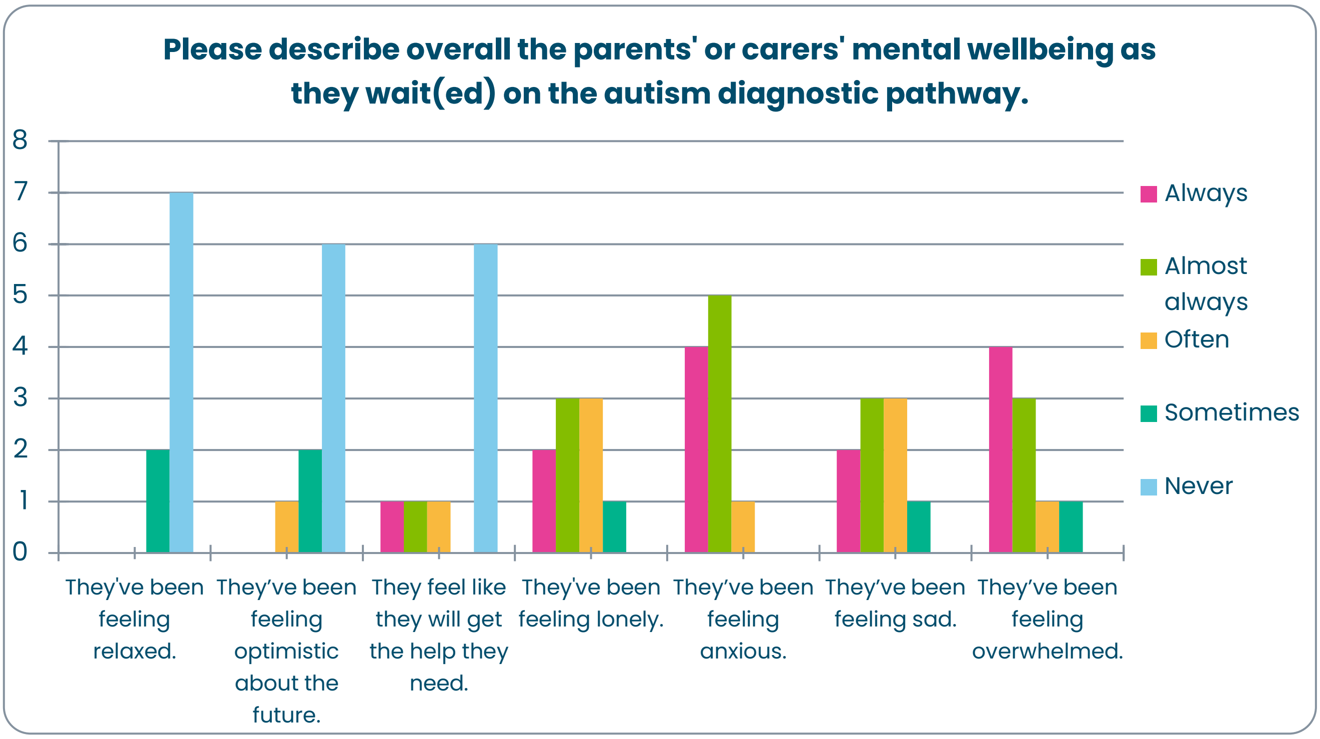
All 10 of the educational professionals reported that parents/carers they interacted with 'never' felt relaxed and there was a high level of anxiety reported, with respondents describing parents/carers as feeling anxious 'always' or 'almost always'. Respondents highlighted that the lack of information for parents/carers regarding when they will get an appointment led to these feelings of anxiety. They noted that parents/carers do not receive updates on waiting times and there is no point of contact to get this information. Financial implications of waiting were also acknowledged as a stressor, with respondents mentioning that some families feel forced to look at costly private alternatives because of long waiting times.

'Thank God we had £1,500 to get him diagnosed [privately]. Because I don't know what we would have done, he definitely would be permanently excluded.' - Parent of a child who was on the Emerging Needs Pathway

'Not everybody can afford it. Some people do it and it's a real stress. Some people ask their family [for money] to do that.' - Parent of a child on the Emerging Needs Pathway

'It puts a strain on the whole family and can lead to break downs in relationships.' – Educational Professional

Parents/carers were also described as feeling sad and overwhelmed by the 10 educational professionals with comments highlighting that parents/carers feel like they are in limbo while waiting for an assessment for their child.



> ***'Parents/carers often feel frustrated. In Wandsworth you can't access a certain school without this diagnosis so their children cannot access the setting they need.'*** - SENCO

3.2.5 Available Support for Parents/Carers

We asked educational professionals if they were aware of parents/carers accessing support for themselves while waiting for a diagnosis for their child. The responses were more split, with 40% of respondents saying that they are aware that parents/carers have accessed support while waiting for an autism diagnosis, and 40% said they were not aware of this. The remaining 20% were unsure. Respondents have suggested that some parents may find it difficult to access support for themselves due to language barriers, having a disability, or work commitments.

> ***'But it's still taking two years, despite me spending hours and hours trying to find who could help and some parents can't do that because they have several kids, they are working. Some parents might not know English very well.'*** – Parent of a child on the Emerging Needs Pathway

On the positive side, all 10 educational professionals said that children on the pathway they interacted with have been able to access speech and language therapy (SALT) which is in line with what we heard from parents/carers. SALT was seen as particularly beneficial. 80% of professionals said that children were able to access occupational therapy and 60% reported children accessing psychological support. None of the respondents reported that children were accessing psychiatric support.

We asked educational professionals what supports they believe had been the most helpful, here is what they said:

- Wandsworth Autism Advisory Service (WAAS)
- Early Years SEND Inclusion Team
- Wandsworth Information Advice and Support Service (WIASS)
- Speech and Language Therapy (SALT)

3.3 Discussions with statutory and voluntary organisations

With our focus on the local situation within the borough of Wandsworth we reached out to NHS SWL ICB in the summer of 2024, to understand the status of the Emerging Needs Pathway in the borough.

Following this, it became clear that NHS SWL ICB were aware of some of the problems being faced by those using the pathway and that they were in the process of redesigning the system. With NHS SWL ICB's support we reached out to a variety of statutory and voluntary organisations to get feedback about the current state of the pathway and what changes they wanted to see in the redesign.

As part of this process, we spoke to various stakeholders including representatives of Wandsworth Council's Children's services, voluntary organisations focused on SEND children, and NHS SWL ICB representatives. The full list of stakeholders we spoke to can be found in the appendix.

From these discussions a variety of themes arose. We have allotted these into six major themes:

- The current pathway and goals of the redesign
- Health inequalities & stigma around autism
- Importance of early intervention
- Role of voluntary organisations
- Support available during waiting & Education Health Care Plans (EHCPs)
- Support after formal diagnosis

3.3.2 The current pathway and goals of the redesign

Speaking to a variety of stakeholders it became clear that there was broad agreement that the current pathway was not achieving its intended purpose and needed a redesign. The Emerging Needs Pathway had been previously redesigned in 2018/19 following a public consultation with residents. However, due to a combination of factors the redesign was not able to solve existing issues, and waiting times on the pathway began to increase. The increased waiting times were acknowledged by all stakeholders as well as the reality that the current system cannot deal with the demand for new referrals. Additionally, it was recognised that the long wait times were often due to the requirement of multiple evidential documents from different individuals before a formal assessment could take place. Often all required documents were not collected in the set timeframe, and documents would go out of date. Parents/carers would then need to restart the process of collecting updated versions of these documents.

While the previous redesign in 2018/19 had focused on addressing residents' desires for more support while waiting on the pathway, voluntary organisations that work with parents/carers expressed that parents often tell them they do not feel they are able to access appropriate supports without a diagnosis. In response to this Wandsworth Autism Advisory Service (WAAS) stated that *'the only part of the service not eligible prior to a diagnosis is the post diagnosis parents training. The rest of the vast universal service is open to all parents whilst they are awaiting a diagnosis. As with all other services, funding restraints has meant that new ways of offering support is always at its core'*

'Our preference is for him to be moved to an ASD resource based [school] and those ASD resource bases are managed by the council and most of them, when you talk to them, they will tell you they need the diagnosis' – Parent of a child on the Emerging Needs Pathway

Regarding the new redesign of the pathway, many of stakeholders we spoke to suggested that the new pathway should take a holistic approach in which there is joined up working between different sectors to provide support for the child and their family. However, while this was seen as the ideal approach to the pathway there was also an acknowledgment that the current situation is a crisis with a large backlog of children on the waiting list and that a focus on providing formal assessments to clear the list is the priority. Once the situation is manageable, it was acknowledged that there should be an eventual move towards a holistic and needs-based approach. This was echoed by voluntary and other organisations who stressed that parents want a formal diagnosis to access supports, but that needs-based support on a case-by-case basis would prove to be more effective.

3.3.3 Health inequalities & stigma around autism

Another theme that emerged and which reflected our findings i the literature review was the impact of health inequalities on the process of getting an autism diagnosis. Speaking to an organisation that deals with a large cohort of Somali residents in Wandsworth we heard of how there is still existing stigma around neurodevelopmental conditions such as autism due to misinformation about its implications. This has led to some parents becoming defensive around seeking a diagnosis when they are advised to by healthcare or educational professionals.

This has contributed to an underdiagnosis in the Somali community and lack of support in addressing autistic individuals' needs. However, it was also suggested that this is also partly a result of a lack of capacity of healthcare organisations to target these communities and provide education and information around neurodevelopmental conditions. Community groups are now starting to work with their own members who have firsthand experience and supporting them to inform others of neurodevelopmental conditions such as ASD/C. It was also acknowledged that support services and the diagnosis process will need to acknowledge cultural differences to be more approachable and meet their needs if they want better engagement.

3.3.4 Importance of early intervention

Another common theme raised by a range of stakeholders was the belief that early intervention for autistic children was vitally important. For the NHS, the local authority and other healthcare organisations this goes in line with their shared approach towards a preventative healthcare system, which is proactive rather than reactive. This not only reduces financial costs in the long term by reducing the need for more intense interventions at a later stage in life but also allows for autistic children to be supported from an earlier stage and improve their quality of life.

> ***'He'd [have] developed those skills, and he'd make a much more meaningful contribution to society when he's older'*** – A parent on the importance of early and appropriate intervention

It was also acknowledged by a voluntary organisation that deals with autistic people of all ages that while there is often limited support for children and young people there is nearly no support networks for autistic people that are 18 or older, and that often to receive formal support for adult social services a formal diagnosis will be needed. Therefore, getting this diagnosis early can make the transition to later life easier and ensure a continuity of support.

> ***'It feels that the understanding in social care comes with the autism diagnosis…we need the autism diagnosis to help him access disabled children's [support] and later on adult services'*** – A parent of an autistic teenager

3.3.5 Role of voluntary organisations

Both statutory, as well as the voluntary organisations themselves, acknowledged the important role they play in supporting both autistic children as well as their parents/carers. Parent/carers often rely on a network of organisations that provide support for them while they await a formal diagnosis. Furthermore, even for those who do receive a formal diagnosis, and are able to access the extra support this enables, there is still often a need to utilise various organisations to feel fully supported.

Effective signposting to the various voluntary and statutory organisations that offer this support in the borough was highlighted as extremely important. Organised networks that provide parents/carers this information through WhatsApp groups or mailing lists help to make sure residents are aware of events and opportunities that are happening. Nevertheless, it was also raised by many of the voluntary organisations we spoke to that there is not enough funding or capacity to provide the level of consistent support parent/carers, and their children, require. It was also noted that the school holidays are a difficult time for this when support provided by an educational setting is removed.

> ***'Autism doesn't only last from 9-5 Monday to Friday, relevant support is required 24/7'*** – Local voluntary organisation lead

Statutory organisations also acknowledged the need to move to a more joined up approach with healthcare professionals, who provide clinical support, working alongside – and signposting to – other organisations that offer relevant support, such as drama therapy. Currently there is the view that clinical teams sometimes undervalue these non-clinical support organisations and therefore do not make parents/carers aware of them.

3.3.6 Support available during waiting & Education, Health and Care Plans

All the stakeholders we spoke to recognised the importance of parents/carers and their children being supported during the often lengthy waiting period on the pathway. They suggested that, ideally, the support offered during the waiting period would be identical to that provided following formal diagnosis and be needs-based. Additionally, the organisations we spoke to stated that parents/carers are often told that they needed an EHCP to access a range of support services, therefore this added to the importance of having this plan alongside also seeking a formal autism diagnosis.

In response Wandsworth Children's Services stated that the SEND Code of Practice (2015) outlines that *"Support should be put in place according to presenting needs and should not be dependent on any formal diagnosis."* [17]

> ***'So, for my son initially we had the EHCP, and we had an agreement for funding for a home education programme and that was perfect for him. That's just what he needed, and we felt that we were being really listened to'*** - Parent of an autistic teenager

> ***'Having the EHCP, it wasn't a diagnosis, but what it gave us was access to support'*** - Parent of a child who was on the Emerging Needs Pathway

As mentioned before, a major issue raised was that there is a difference between the limited awareness parents/carers have of support they can access while on the wait list, and the actual range of support that is available to them. Often there is confusion and no clear picture on what services, interventions or supports are available for those without a formal diagnosis. Statutory organisations acknowledged that there is a lack of clear communication and that there should be a centralised hub that offers a clear list of supports available and their access requirements. There was also an acknowledgement that there is less support available than needed due to a lack of funding and staffing in early years support. A stakeholder also stated that they are aware that previously a lot of support was dependent on children being in an educational setting and that there is now a desire to support those that are not in that setting and those who have not been aware of or able to access support previously.

3.3.7 Support after formal diagnosis

Another key theme mentioned was the disconnect between the perceived benefits that will come with a formal autism diagnosis and the reality of the support available. While many of the organisations we spoke to supported and understood parents/carers desire to get a formal diagnosis, they reflected that those who had received it found little changed. This perception was felt to have a knock-on effect for other parents/carers who become apathetic towards seeking a diagnosis or support in general because they believe it will not have a positive impact on their lives.

NHS SWL ICB also noted that there are significant expectations that with a formal diagnosis signed off by medical professionals, parents/carers and their children will be able to get all the support they need through statutory organisations. This

---

[17] https://search3.openobjects.com/mediamanager/wandsworth/fsd/files/ordinarily_available_provision.pdf

echoes the move towards a holistic approach that many stakeholders suggested; that rather than a system of support responding to a diagnosis, there should be a system that is needs-based and provides relevant support in a timely manner.

> ***'All I remember of the day of his diagnosis was that she confirmed it and said we didn't have to tell his grandparents if we didn't want to. I took nothing away from that day'*** – A parent on receiving the formal diagnosis of autism for their son

> ***'Once you've got [the] diagnosis, where do you go with it? Because there seem to be very limited options'*** - Parent of an autistic teenager

In response to these comments staff at St George's Hospital highlighted that *'a post-diagnostic appointment is offered to families for further support after the Multidisciplinary Assessment'*.

4. Recommendations and Ideas for Improvement

As a result of speaking to 52 parents/carers, 10 SENCOs and educational professionals, and various statutory and voluntary organisations, and combining this with the recommendations found in the 40 articles/reports in our literature review, Healthwatch Wandsworth has put forward **eight key recommendations** for improving the experience of parents/carers and young people and children on the new Social Communication Difficulties Pathway. These recommendations align closely with the 2023 national framework and operational guidance NHS England has developed for integrate care boards in relation to delivering improved outcomes in all age autism assessment pathways.[18]

4.1 Improved Communication

A common issue faced by parents/carers on the pathway we spoke to was the lack of communication around:

- their child's status on the pathway

---

[18] 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/#foreword
https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#overview

- when they would receive further contact

- and in many cases, not actually knowing if their referral to the pathway had been accepted

The system appeared to be more reactive, communicating once an appointment has been arranged, rather than keeping people up to date with information they need as they are waiting and helping them understand the steps they will have to take. This was also reinforced by SENCOs who often found it difficult when advocating for parents/carers to find out about a child's status.

'We never got any update about anything. It was just "Here's an appointment in a year's time."' - Parent of a child who was on the Emerging Needs Pathway

'Nobody answers back to you, just to tell you "Listen, we know it's hard. We are really sorry. We wish it would be otherwise, but the waiting list is three years." No, there's just nothing.'- Parent of a child on the Emerging Needs Pathway

Recommendation for NHS SWL ICB & local authority

We would suggest there is a strong need for better communication among all stakeholders involved in the diagnosis and support process. Parents/carers expressed feelings of being left in the dark, with many of those we spoke to suggesting that regular updates and clearer communication about waiting times and processes would alleviate their anxiety and confusion. NHS England's 2023 operational guidance recommends every three months with an opt out option for the person if they do not wish to receive these updates.[19]

This was also supported by reports and articles in the literature review with better communication between all parties involved being recommended in 14 separate papers.

We have also been investigating whether the hospital patient portals and the NHS App can provide a platform for communication and tracking progress and waiting times. Unfortunately, the systems are not yet in place for this to happen currently, but we will continue to monitor and encourage progress on this.

Potential Impact

By implementing improved and more consistent communication, stress and anxiety for parents/carers would be reduced as they would become more aware

---

[19] https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#stage-3-pre-assessment-support

of their status on the pathway and expectations can be managed with a clear acknowledgement of the steps that will be taken and the waiting times associated with these.

Improved and transparent communication would also create more trust with the system and service providers, where parents/carers would feel that the information they are receiving is accurate and non-conflicting.

4.2 Interdepartmental Collaboration

Closely in line with improved communication with users was a desire from parents and education staff to see those within the system themselves communicate more effectively and collaborate further.

> ***'So, you're just lost in this advice. And none of it joins up because the system doesn't join up'***
> - Parent of a child who was on the Emerging Needs Pathway

Recommendation for NHS SWL ICB

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

Potential Impact

This collaboration could streamline the assessment process and ensure that all relevant information is collected in a timely manner when diagnosing and supporting children.

This would help to alleviate gaps in information collection which has been acknowledged by service providers as a reason for delays in autism assessments. This would also prevent the duplication of information collection which is time consuming for both service providers and service users.

Interdepartmental collaboration would also allow for more effective and efficient signposting and information sharing between all parties involved, therefore helping to ensure parents/carers and their children receive appropriate support in more timely manner.

4.3 Multi-Disciplinary Assessments

Looking long term there was a strong call from parents/carers and voluntary organisations for multi-disciplinary assessments that can address common co-occurring conditions, such as ADHD and ASD/C, in a more integrated and holistic manner. This is particularly relevant given the fact that comorbidity between ASD/C and ADHD has been acknowledged in an NHS study as potentially between 1/3 and 2/3rds in children.[20] Parents noted that waiting for separate assessments can prolong the time before receiving necessary support.

The consideration for a broader single Neurodevelopmental Pathway that addresses ASD/C, ADHD, and other neurodevelopmental conditions was also recommended by three texts in our literature review.

> ***'So having this kind of piecemeal approach is really hard. You shouldn't have to keep going through assessment after assessment rather than a holistic approach, it takes too long in that way.'*** - Parent of an autistic teenager

Recommendation for the NHS

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

Potential Impact

This would help alleviate collective waiting times for parents/carers to receive support for their child's neurodevelopmental conditions. There could also be potential efficiency savings for NHS SWL ICB and local authority services.

Furthermore, as acknowledged by two texts in our literature review, by moving towards a holistic approach in dealing with neurodevelopmental conditions it could help create a society more accepting of neurodiversity and increase a willingness in parents/carers and communities to engage with clinical assessments.

4.4 Clearer Processes and Guidelines

Other issues raised by parents/carers and educational professionals were difficulties in understanding how to access the Emerging Needs Pathway and what supports are available with and without a formal diagnosis. This was an issue raised by six papers in our literature review indicating that this is not an issue unique to Wandsworth.

---

[20] NHS Health Research Authority 'The prevalence and profile of ADHD features in children and young people with autism spectrum disorders.' Published 26 July 2016 https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/features-of-adhd-in-children-with-asd/

There was also frustration around the lack of clarity around which statutory organisations and professionals are responsible for what in relation to the pathway and support.

Parents/carers as well as educational professionals were also often confused about the best route to refer into the Emerging Needs Pathway with seemingly different approaches having different rates of success. An emphasis on having a simplified and streamlined pathway was recommended in 14 papers in our literature review.

'I think it took another two years to get a face to face [appointment] with a paediatrician, the same paediatrician. Who said "He needs an autism assessment but he's now too old to be assessed for autism at St George's" which was just devastating because he was 8, the cut off at Saint George's is 7 ½ and he'd been on that waiting list since he was 5.' - Parent of a child who was on the Emerging Needs Pathway

'I guess sometimes I do struggle to understand exactly what the pathway is and everything which is in it' - Parent of a child who is on the Emerging Needs Pathway

Recommendation for NHS SWL ICB

We would recommend that a clear outline of the process of how to access the new Social Communication Difficulties Pathway is made public and widely distributed to all relevant parties.

We would also suggest that a central directory is created and actively updated detailing all the relevant supports available for autism in Wandsworth and the conditions for accessing them. We are aware that this exists in some capacity through the Wandsworth Family Information Service but that a specialised ASD/C related directory would be beneficial.

Potential Impact

A clear outline of how to access the pathway would increase the efficiency of referrals into the pathway, making sure that parents/carers can begin to access available support as soon as possible.

The creation of a central directory would reduce the instances of parents/carers being unaware of the support/interventions they are entitled to access. This would in turn make them feel more supported by the system, reduce anxiety and stress over their child getting appropriate help and in the long term reduce more complex needs for the children later in life that would require more intense and costly interventions.

4.5 Early Intervention

From talking to statutory and voluntary stakeholders, as well as parents/carers and educational professionals, providing early intervention for those with emerging needs was seen as vitally important.

There is a consensus that earlier assessments and interventions could significantly benefit children. Parents/carers suggested that regular check-ups and developmental screenings should be implemented to identify potential needs sooner. In addition, creating a culture in which parents are encouraged and feel empowered to refer their children for assessment early on after they or educational/healthcare professionals notice atypical development was also recommended by five of the texts in our literature review.

'Those Emerging Needs Pathway delays impact on the teenage years because our children age out of the system quite quickly. It's not a very long time between 8 and 18.' - Parent of an autistic teenager

'I think the worst part is that I'm scared that we're going to access support too late' – Parent of a child on the Emerging Needs Pathway

Recommendation for the NHS SWL ICB & local authority

We would recommend that all parents/carers are informed 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 a child's potential emerging needs.

Potential Impact

This would ensure that children with atypical development are not missed early on and would allow for relevant support to be offered progressively as needed, further preventing more costly interventions later due to the lack of prior support.

4.6 Training and Education

There was widespread agreement that there should be more training and education for those in healthcare, social care and education to recognise and identify children with autism and related conditions.

Besides parents/carers, educational professionals are often the individuals who interact the most with children during their developmental years, yet it was made clear by parents/carers and educational professionals themselves that the experience and knowledge of school staff around neurodevelopmental conditions like autism is often varied. This in turn has led to parents feeling they need to move their child to schools with a more experienced SENCO to get the appropriate support they need. In addition, educational professionals or schools who have not been trained or educated to handle neurodevelopmental conditions such as autism were seen by parents as unable to support their child's development in school.[21]

This has also been echoed in the healthcare field. Parents/carers have stated that they have gone to their GP for support, but their GP said they do not know what the appropriate steps to take would be for someone who suspects their child of being autistic. It was also acknowledged in the literature review that CAMHS in some instance provided inappropriate treatment, or did not support people appropriately due to a lack of understanding around autism. [22]

'With the school, with the Educational Psychologist, with Social Workers we were saying "We think there needs to be some assessments of their additional needs" and we kept being told off "No. Why do you want to label your children?" It was quite bizarre' - Parent of an autistic teenager

'There's a lot of autism awareness stuff going on but there needs to be more.' - Parent of a child who was on the Emerging Needs Pathway

Recommendation for NHS SWL ICB & local authority

We would recommend that there is an emphasis placed on providing a standard level of training and education to all relevant healthcare, social care, and educational professionals to allow them to better understand what neurodevelopmental conditions are and who they should signpost parents/carers to for further support.

Potential Impact

This would empower professionals to speak to parents/carers openly about what they are observing in their child and potentially encourage them to seek a referral. It would also increase confidence for parents/carers that the

---

[21] International Journal of Health Care Quality Assurance. 'Understanding and improving the care pathway for children with autism' https://repository.uwtsd.ac.uk/id/eprint/918/1/Hurt.%20L.,%20Lanhley,%20K.,%20North,%20K.,%20and%20Southern,%20A.%20...et%20al%20(2018)%20Understanding%20and%20improving...pdf

[22] Healthwatch Wiltshire. 'Mental health and autism: Falling between the gaps.' Published 23 October 2023. https://www.healthwatchwiltshire.co.uk/report/2023-10-23/mental-health-and-autism-falling-between-gaps#:~:text=This%20report%20highlights%20the%20findings,over%20the%20last%20three%20years

professionals they are speaking to and seeking support from are knowledgeable on the autistic spectrum condition and can offer suitable advice and support.

By creating a society in which more professionals are knowledgeable of neurodevelopmental conditions we would reduce the cases of children with emerging needs that are not identified.

4.7 Holistic Support During Waiting Periods

One of the most common themes that came out from our findings was that if waiting times for a formal assessment are to be lengthy there must be appropriate and widespread support available during this waiting period not only for children but also their parents/carers.

Many of the parents and voluntary organisations we spoke to expressed concern about the lack of support that can be accessed while waiting.

In addition, respondents to our parent/carers survey stated that there is also limited dedicated support for themselves in terms of respite and mental health support during the waiting period, with the existing supports being described as too intermittent to have a continual positive impact. Voluntary organisations who support children and/or their parents/carers often stated that they would provide more support and at a higher frequency if they were given more funding.

'I understand there is a waiting list, and I get that so many kids have autism, I really understand that, but then they should then change the system because so many supports, we can't access because he doesn't have a diagnosis.' - Parent of a child on the Emerging Needs Pathway

'It's hard, It's extremely hard in terms of your mental health. You're caring for an incredibly vulnerable person.' - Parent of an autistic teenager

'It's so lonely and scary having a child that isn't talking, and you feel so powerless to help, but you don't get any time with therapists' - Parent of a child who was on the Emerging Needs Pathway

Recommendation for NHS SWL ICB & local authority

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, that a focus must be placed on providing a range of appropriate and frequent supports and interventions, in collaboration and utilising voluntary organisations, for children and their parents/carers on the waiting list.

Potential Impact

This would ensure children are well supported during the long waiting period, in turn reducing the stress and anxiety parents/carers often feel due to their child's emerging needs not being met while on the waiting list.

4.8 Feedback Mechanisms & A Culture of Listening

Finally, one theme that has been continuously mentioned by parents/carers throughout this project is that they do not feel listened to. Parents/carers were firm in the opinion that while they may not be experts on the medical side of autism spectrum condition, they are often experts on their own children and understanding what supports would help them. Many of the parents/carers we spoke to felt that often their opinions are dismissed, and they have no place to have an open discussion with service providers about their child. Furthermore, they also mentioned that when they do receive supports or go through the Emerging Needs Pathway there is no way for them to provide feedback on what worked well and what could be improved.

'The whole thing is confusing, isolating, and I found that professionals were quite antagonistic with me if I had a different opinion or a question, I just got treated that I was in denial. It's just not a very nice experience' - Parent of a child who was on the Emerging Needs Pathway

'Meeting a professional that seemed to really understand that "yes, your child has additional needs. And yes, you're a fantastic parent and we're not going to blame you and we're going to do our best to see how we can meet those needs with the EHCP." And that was just brilliant.' - Parent of an autistic teenager

'We should we have complained. Would anything have happened differently? I don't know. Probably not.' - Parent of a child who was on the Emerging Needs Pathway

'We went privately in the end because we weren't listened to.' - Parent of a child who was on the Emerging Needs Pathway

'It really feels like nobody really cares. That's how it felt honestly' - Parent of a child on the Emerging Needs Pathway

Recommendation for the NHS SWL ICB

We would recommend that the Social Communication Difficulties Pathway integrates a tool for formal feedback mechanisms to develop a culture of listening which considers parents/carers' and their children's experiences as vital to its design. This is in line with the 2023 national framework NHS England has developed for integrated care boards to deliver improved outcomes in all-age autism assessment pathways.[23]

Potential Impact

This would ensure that service providers become aware of what supports and elements of the pathway are working well and what are the issues. Additionally, it would ensure that future changes to the pathway are designed with the service user in mind. This emphasis on the co-production of support services and the pathway itself was recommended by 10 texts in our literature review.

Recommendations Conclusion

Healthwatch Wandsworth hopes that service providers and those associated with new Social Communication Difficulties Pathway, as well as other relevant providers, will take on board our **eight key recommendations,** to ensure that the new pathway works for local people. These recommendations are based upon what we have heard from local parents/carers, SENCOs and educational professionals, and statutory and voluntary organisations, combined with background research into the national context around autism spectrum diagnosis. These recommendations align closely with the 2023 national framework and operational guidance NHS England has developed for integrate care boards in relation to delivering improved outcomes in all age autism assessment pathways.[24] We look forward to following up with relevant stakeholders after the Social Communication Difficulties Pathway is implemented to see if our recommendations have had an impact on the service user experience.

---

[23] 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/#monitoring-and-evaluating

[24] 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/#foreword
https://www.england.nhs.uk/long-read/operational-guidance-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/#overview

5. Feedback on our recommendations

In April 2024 we sent a draft version of this report to the various parents/carers, educational professionals, and stakeholders that contributed to our project.

We asked parents/carers and educational professionals to share their thoughts on our recommendations:

A SENCO stated *'From my perspective the most relevant and impactful recommendations are those focused on early intervention, cross-agency collaboration, and staff training around neurodiversity'*

'I'm currently working with the wellbeing services in Wandsworth to begin gathering ideas on how we can introduce conversations about neurodiversity in schools'

A local parent stated *'it's a very clear and focussed report. My only suggestion is to include Fetal Alcohol Spectrum Disorder (FASD) in the list of conditions to consider as part of a Multidisciplinary Assessment'*

We also asked stakeholders to give their feedback on our recommendations and asked them to answer some key points we wanted to touch upon:

Is there anything that particularly strikes you about our findings or our recommendations?

WAAS stated that they think *'the report is really useful for the leadership to have, [having] the parents' lived experiences at the centre to enable them to make the right decisions'*

A representative from the local authority stated *'This has been a great piece of work undertaken and hopefully decisions have already been made and started to be put in place that address some of these historic and current issues.'*

'Going forward, hopefully making reference to the suggestions for improvements through your report and the voice of parents/carers contained within it, will help to ensure that changes are implemented for the better.'

WIASS stated that *'The findings echo everything parents inform us of'*:

- *'Lack of updates/communication for some parents, they heard nothing despite calling/emailing'*

- *'The wait times were too long, some have waited over 2 years, only to be told that they child is too old'*
- *'Parents are confused by the assessment process/pathway, when their child will be assessed, and did not know what to expect during the assessment'*
- *'Parents are told their child cannot access a particular setting without a diagnosis, meaning they are in placements that cannot meet their needs, because the schools (Mainstream) do not have the understanding that children mask and that impacts referral'*
- *'Uncertainty affects their children at school with lack of support'*
- *'Impact on the child's and parents' mental health, breakdown of relationships and distress caused'*

What already exists or is in development that might address our findings and recommendations?

WAAS stated that *'there has been significant progress on the pathway and the redesign. Parents have been contacted and updated on wait times, the support element is still as strong as ever and there is a real commitment and shift to make the process more neurodiverse affirming and progressive'*

In your opinion what are the quick wins that can be implemented from our recommendations?

WIASS stated *'Better communication, this must surely be the first stage – keeping parents aware of the process and what to expect. Updating parents on timescales / assessment process - a single website/directory. A point of contact on the ENP – phone or email including clear achievable response times, and where to take a complaint'*

SEND Parent Carers in Wandsworth stated the following should be priorities:

- *'A phone line for parents'*
- *'A list of services that they can access whilst waiting that is given out by the referrer (GP or SENCO or other professional) it could also be sent out by the ENP when they receive the referral'*
- *'Creating a support group for the people on the list (talks and coffee mornings) - or at least in the short term letting the parents know that they can attend the WAAS coffee mornings and talks even if they don't have a diagnosis. Better advertising of the fact that WAAS run a 'PACT' course for parents about parenting a child with autism'*
- *'Occupational Therapy - need more OT's so that they can offer face to face appointments to those on the waiting list'*

WAAS stated that they saw *'communication to families, training for professional, early intervention and clearer process and guidelines'* as quick wins and that these were all already in progress.

In your opinion what are the more challenging things to implement in our recommendations and how can they be overcome?

WIASS stated *'The more challenging things will be resourcing the recommendations, and the time it will take and what will happen in the short term'*

'The key barriers to training and upskilling professionals in educational settings are funding and time; new training programs can take time to formulate, deliver and implement, and successfully addressing the culture within schools around SEN is often determined by the leadership within any specific setting'

WAAS stated that they saw interdepartmental collaboration as difficult *'due to national standards and data protection'* alongside multi-disciplinary assessments as *'NHS and Nice guidelines indicate that autism and ADHD are separate routes for diagnosis and combining may be complicated although not impossible. But this would need national statutory change.'*

6. Official Responses

6.1 NHS South West London Integrated Care Board (NHS SWL ICB) Response:

'We are grateful to Healthwatch Wandsworth for facilitating this important piece of work. It is incredibly valuable to receive feedback from parents, carers, and professionals in shaping the new diagnostic pathway and ensuring that children and their families receive the appropriate support both before and after diagnosis.'

'The ICB has already taken action on the eight key recommendations and is working closely with the Local Authority on those that fall within their remit. For example, all parents and carers of children on the pathway have been contacted, and a dedicated enquiries email address has been created. All correspondence from parents, carers, and schools is now responded to on a weekly basis.'

'The ICB and Local Authority have launched a number of workshops and information sessions through the Wandsworth Autism Advisory Service (WAAS), which are now available pre-diagnosis, along with other forms of support for children and families. Feedback to both Healthwatch Wandsworth and the ICB has shown that parents and carers find this pre-diagnostic support helpful.'

'Despite a significant additional investment of over £600,000 per year into the new diagnostic pathway and increased capacity, waiting times are expected to take several years to align with those in other South West London boroughs due to the high volume of referrals. However, a range of mitigations has been put in place to ensure early support is available through Ordinarily Available Provision in nurseries and schools. Where a fast-tracked assessment is needed to support decisions around potential Special School placements, this is being actioned.'

Improved Communication

- *The ICB has created a dedicated enquiries email address and contacted all parents and carers of children on the waiting list with updates. The Core Offer website has been updated with relevant information, and all stakeholders have been informed of progress on the new pathway.*
- *St George's has increased administrative capacity within the new team to enhance communication.*
- *The ICB continues to contribute to funding for pre- and post-diagnostic support provided by Local Authority and Health teams, including workshops, behavioural support, and early interventions.*

Interdepartmental Collaboration

- *A Task & Finish Group, led by the ICB and including all partners, is working collaboratively to improve outcomes for children and families.*
- *A quarterly Children's Programme Board and CAMHS Partnership Meeting monitor progress on the diagnostic and support pathways.*
- *A monthly professionals' group addresses collaboration challenges, particularly around children being passed between services. This has clarified appropriate support routes and reduced inappropriate referrals.*

Multidisciplinary Assessments

- *The new pathway includes a multidisciplinary team.*
- *The feasibility of assessing a small number of children aged 0–8 for both autism and ADHD by St George's clinicians is being explored. However, due to clinical and practical reasons, most children referred for both conditions will need separate assessments. Efforts are being made to communicate this clearly to parents and carers and to identify opportunities for efficiency.*

Clearer Processes and Guidelines

- *Parents and carers have found the new pathway diagram helpful. Some prefer a simplified route to access the appropriate service, such as the Child Development Centre for 0–8-year-olds and the CAMHS Single Point of Access for 8–18-year-olds.*

- *Additional referral pathways will be introduced later in 2025 in a simplified format, providing clarity on triage, evidence gathering, and assessment stages.*

Early Intervention

- *The Local Authority is developing a new email address for health professionals to notify them early when a child may have Special Educational Needs or Disabilities (SEND), enabling timely support through Ordinarily Available Provision and Early Help.*

Training and Education

- *Relevant training has been identified to ensure staff are appropriately skilled.*
- *All staff now complete Oliver McGowan Training, contributing to a growing understanding of autism, neurodiversity, and social and communication difficulties.*

Holistic Support During Waiting Periods

- *A Neurodevelopmental Clinical Nurse Specialist will support clinical communications regarding the diagnostic pathway.*
- *The Local Authority is expected to provide information on early interventions, including expanded pre-diagnostic support from WAAS, which parents and carers have found very helpful.*

Feedback Mechanisms & a Culture of Listening

- *The redesign of the pathway and communication with parents and carers on the waiting list have provided valuable insights into family experiences. This has enabled the ICB and partners to support families pre-diagnosis and fast-track referrals where a special school placement is needed.*
- *There is a strong commitment to ongoing feedback from parents and carers, close collaboration with partners and the Parents & Carers Forum, and a comprehensive review of the new service within a year of its launch, with parent and carer involvement.*

6.2 St George’s Hospital NHS Foundation Trust (SGH) Response:

‘We agree with the information contained in this report that it is reflective of people’s experience of the current pathway. [The] report demonstrates that individuals spoken to were unclear on what the ENP, ICB and SGH are. New pathway needs clear information on who and how the pathway is managed.’

‘We agree with the eight key recommendations and are working on these as part of our new pathway and will continue to review the recommendations to improve our service.’

Improved Communication

- *We will have 2 new administrative team members to support managing communication for our Neurodevelopmental service regarding the diagnostic pathway.*
- *We will have a Neurodevelopmental Clinical Nurse Specialist to support clinical communications.*
- *Service will be able to give estimated waiting timeframes.*
- *All pathways will be tracked with clear timeframes, set against an 18-week referral to treatment target*
- *Draft communications have been written to share with parents/carers at set points in the pathway.*
- *We expect the Local Authority to provide communication regarding early interventions.*

Interdepartmental Collaboration

- *There are multi-agency meetings set up to oversee this new pathway including the ICB, LA and SGH.*
- *The pathway has been designed with medical, psychology, operational and therapy colleagues at SGH.*
- *We will continue to work with the LA to ensure patients are still able to access early help when needed.*

Multidisciplinary Assessments

- *We have created a new diagnostic model including psychology-led diagnostic assessments*
- *We are introducing a Neurodevelopmental Clinical Nurse Specialist into the service.*
- *We have increased operational administrative support for the pathway.*

Clearer Processes and Guidelines

- *We have created a detailed referral pathway which will be backed up with written SOPs for the service.*
- *The pathway will be tracked against an 18-week referral to treatment pathway.*
- *We are building a dedicated webpage for the service with access to pathway details, key contacts, support services in Wandsworth and all key forms required.*

Early Intervention

- *We have built a referral trigger to the Local Authority*

Training and Education

- *We have identified relevant training for professionals to ensure we have the appropriately skilled staff*

- *Our webpage will provide further information for parents and carers on the local offer and educational content.*

Holistic Support During Waiting Periods

- *We will have a Neurodevelopmental Clinical Nurse Specialist to support clinical communications regarding the diagnostic pathway.*
- *We will have 2 new administrative team members to support managing communication for our Neurodevelopmental service regarding the diagnostic pathway.*
- *Our webpage will provide further information for parents and carers on the local offer and educational content.*
- *We expect the Local Authority to provide communication regarding early interventions.*

Feedback Mechanisms & A Culture of Listening

- *We will assess the effectiveness of the service at set points and will collate information from parent and carers.*
- *We will work with the ICB and LA to support cross-service feedback*

7. List of supports and resources

Over the course of this project, we have drawn up a list of supports and resources for autistic children and young people and/or those with social and communication challenges both locally and nationally.

Wandsworth Autism Advisory Service (WAAS) - This is a multi-agency team with professionals from education, speech and language therapy, occupational therapy, and psychology working together to offer support that promotes the inclusion of children with autism in Wandsworth. In addition to school support, they offer sibling groups and groups for autistic children.
Contact details: 020 8871 6882, AutismAdvisory@wandsworth.gov.uk

Wandsworth Information, Advice and Support Service (WIASS) - WIASS is the local information and advice service in Wandsworth for children aged 0-25 with SEND and their families/carers.
Contact details: 020 8871 8065, wiass@wandsworth.gov.uk

SEND in Mind - SEND in Mind provides assistance with the practical and emotional aspects of caring for a child with SEND who is 0-19 years old. They also give advice and information.
Contact details: SENDinMind@bwwmind.org.uk

A2ndVoice - A2ndVoice hosts events for children with SEND and their families. They also offer support and advice.
Contact details: hello@a2ndvoicecic.co.uk

SEND Parent Carers in Wandsworth - This group is run by local parents and carers of children and young people with SEND. They keep fellow parents in the loop about SEND events and changes to SEND provision and signpost to helpful resources in the community.
Contact details: admin@sendpcwandsworth.org.uk

Sen Talk - SEN talk holds events, workshops, support groups, and one-to-one support to families and carers of children with SEN.
Contact details: 020 7223 169, info@sentalk.org

National Autistic Society - The National Autistic Society provides information and support autistic people and their families. Notably, they have a support pack for before, during and after the diagnosis process. Visit their website to access their resources.

IPSEA - A SEND law charity that offers information and advice on how to access entitlements.

Family Information Service - The Family Information Service for the borough of Wandsworth is a comprehensive directory of local services for children, families, and SEND.
Contact details: 020 8871 7899, fis@wandsworth.gov.uk

WAND Card - This is a form of identification showing membership of Wandsworth's Disabled Children's Register. This can provide your child with free and discounted services across the borough from participating businesses.
Contact details: 020 8871 8907, dcrwand@wandsworth.gov.uk

Wandsworth Carers Centre - Wandsworth Carers Centre is a charity that supports unpaid carers in the borough. They offer information, advice, and support groups.
Contact details: 020 8877 1200, info@wandsworthcarers.org.uk

SOS SEN - A charity that supports children and families as they aim to get the right educational provision.
Contact details: 020 4592 3254

Autistica - A research charity that offers information on what autism is and conducts research on autism to shape policy.
Contact details: 020 3857 4340, info@autistica.org.uk

SEN Unity - A charity that combines sports, education, and music to support children of all abilities. They offer a range of sessions in education settings, support for families, and holiday camps.
Contact details: 079 6351 9846

iSensory CIC - On instagram (website coming soon) - A charity that combines sports, education, and music to support children of all abilities. They offer a range of sessions in education settings, support for families, and holiday camps.

Early years SEND inclusion service - The Early Years SEND Inclusion Service is delivered by Richmond and Wandsworth Council. They offer three services: Portage, which is a home visiting service for children aged 0-4 years old with SEND; The Early Years SEND Inclusion Advisory Service, which is a team that supports children aged 3 months to 5 years old with Wandsworth Early Years providers; and the Enhanced Children's Centre which offers sessions for young children with additional needs. Take a look at their webpage for details.
Contact details: 020 8871 5690, monika.hammel-lobo@richmondandwandsworth.gov.uk

Ambitious about Autism - Ambitious about Autism has a parent toolkit with practical tips and checklists that can help you and your family on your autism journey.

Contact: For families with disabled children - Contact offers a range of services, advice and information for families with disabled children. Supporting families, bringing families together and helping families take action for others.

Wandsworth CAMHS Under 5s Therapy Service - A free early intevention service. Team of clinicians who are experienced in working with children under 5 years old. We aim to support health emotional

and social development in children.
Contact details: 020 3513 4644

Beyond Autism Early Years Service - Empowering parents and carers to build the essential skills, knowledge, and confidence to support their children in developing communication and language. The service offers a flexible approach, with attendance designed to fit around the timetable of each family.
Contact details: 020 3031 9703 or earlyyears@beyondautism.org.uk

Little Village - Via our network of baby banks we pass on loved goods from one family to another – clothes, toys and equipment – so that many more babies and young children have the essential things they need to thrive.

8. Become a Healthwatch Member

Make your voice heard in health and social care. Become a member today!

Click here to become a Healthwatch Wandsworth member for free

What do we offer our members?

We champion local voices, and tell you about:

- Events: where you can meet other people, share experiences, and talk to decision makers in health and care.
- Signposting: to free opportunities, services, and community events.
- Volunteering: to give back to the community.
- News: keeping you updated on the latest news.

Healthwatch is an independent champion for **your voice** in health and social care services.

9. Appendix

9.1 List of stakeholders engaged

- A2ndVoice
- Assistant Head of Children's Services (NHS SWL ICB)
- Battersea Cluster (Richmond and Wandsworth Councils)

- Children’s Service equality, diversity and inclusion board (Richmond and Wandsworth Councils)
- Children’s Therapies (St George’s NHS Trust)
- Early Years SEND Inclusion Advisor (Richmond and Wandsworth Councils)
- ELAYS Network
- Family Information Service & Keep In Touch (Richmond and Wandsworth Councils)
- Generate
- Head of Clinical Services, Wandsworth Place (CLCH NHS Trust)
- Healthwatch Merton
- Inclusion Advisor at Wandsworth (Richmond and Wandsworth Councils)
- Kidz4
- Lead Early Years SEND Inclusion Advisor (Richmond and Wandsworth Councils)
- Mind Heart Creative Therapies
- Oasis Putney
- Parent Participation (Richmond and Wandsworth Councils)
- Partnerships and Inequalities (Wandsworth) (NHS SWL ICB)
- Rackets Cube
- Roehampton Cluster (Richmond and Wandsworth Councils)
- SEN Unity
- SEND in Mind Wandsworth
- SEND Local Offer (Richmond and Wandsworth Councils)
- SEND Parents Carers in Wandsworth
- Senior Early Help Practitioners (Richmond and Wandsworth Councils)
- Share Community
- Special Educational Needs and Disability (NHS SWL ICB)

- South West London and St George’s Mental Health NHS Trust
- Tooting Cluster (Richmond and Wandsworth Councils)
- Wandsworth Autism Advisory Service (Richmond and Wandsworth Councils)
- Wandsworth Children's Service's Directorate (Richmond and Wandsworth Councils)
- Wandsworth Information Advice & Support Services (WIASS)
- Wandsworth Locality Teacher (Richmond and Wandsworth Councils)

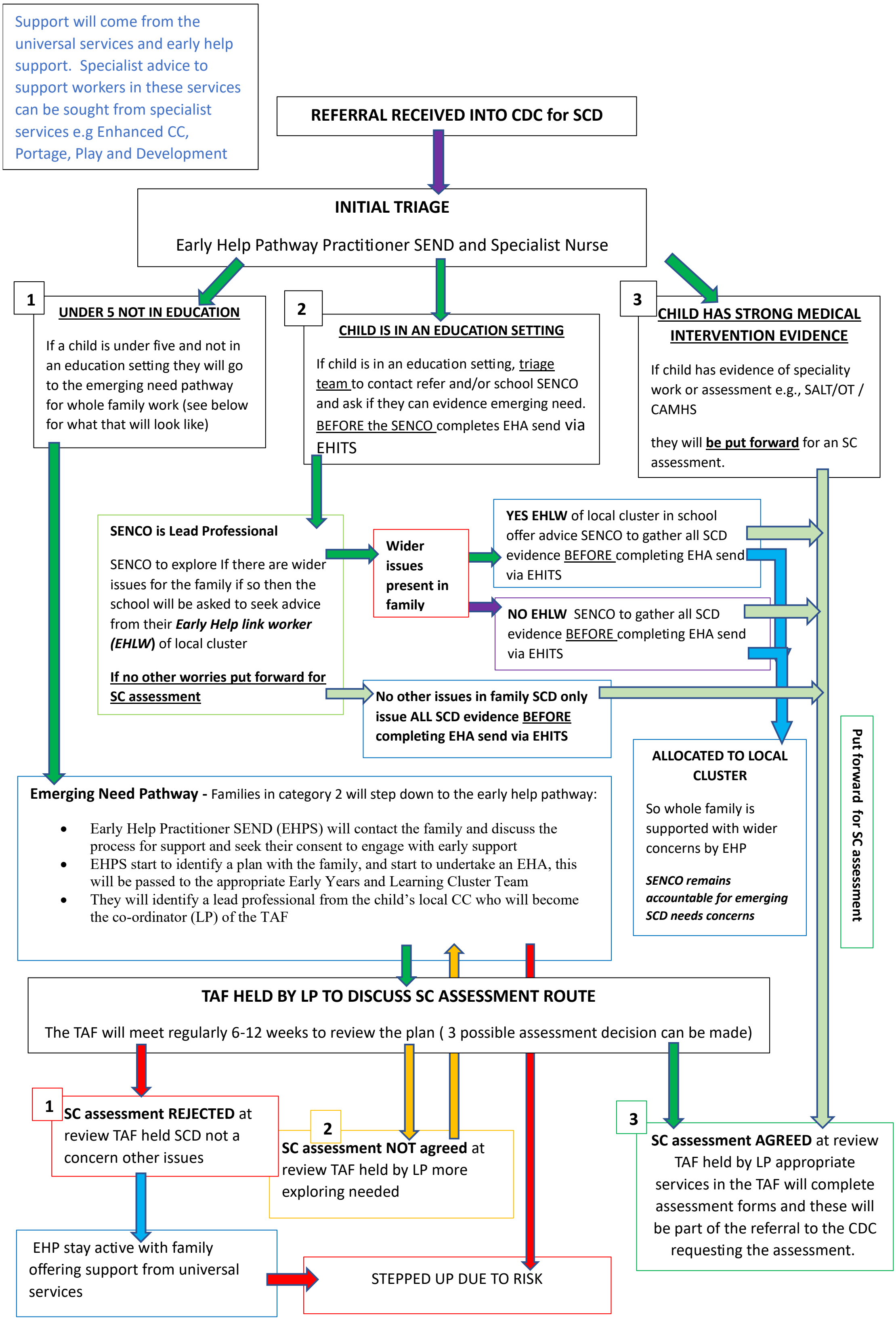
9.2 List of Acronyms

- ADHD – Attention Deficit Hyperactivity Disorder
- ASD/C – Autism Spectrum Disorder/Condition
- CAMHS – Child and Adolescent Mental Health Services
- CPV - Child to Parent Violence
- CYP – Children and Young People
- EBSNA - Emotional Based School Non Attendance
- EHCP – Educational Health Care Plan
- ENP – Emerging Needs Pathway
- FASD - Fetal Alcohol Spectrum Disorder
- HWW – Healthwatch Wandsworth
- MDA - Multidisciplinary Assessment
- MDT – Multidisciplinary Team
- NHS – National Health Service
- NHS SWL ICB – NHS South West London Integrated Care Board
- OCD – Obsessive Compulsive Disorder
- OT – Occupational Therapy
- SALT – Speech and Language Therapist/Therapy
- SCD – Social Communication Difficulties Pathway

- SENCO – Special Educational Needs Coordinator
- SEND – Special Education Needs and Disabilities
- SENDPCW – SEND Parents Carers in Wandsworth
- WAAS – Wandsworth Autism Advisory Service
- WIASS – Wandsworth Information Advice and Support Service
- WCA – Wandsworth Care Alliance

9.3 Emerging Needs Pathway/Social Communication Difficulties Pathway flowcharts

Current Emerging Needs Pathway



Support will come from the universal services and early help support. Specialist advice to support workers in these services can be sought from specialist services e.g Enhanced CC, Portage, Play and Development

REFERRAL RECEIVED INTO CDC for SCD

INITIAL TRIAGE

Early Help Pathway Practitioner SEND and Specialist Nurse

1 **UNDER 5 NOT IN EDUCATION**

If a child is under five and not in an education setting they will go to the emerging need pathway for whole family work (see below for what that will look like)

2 **CHILD IS IN AN EDUCATION SETTING**

If child is in an education setting, triage team to contact refer and/or school SENCO and ask if they can evidence emerging need. BEFORE the SENCO completes EHA send via EHITS

3 **CHILD HAS STRONG MEDICAL INTERVENTION EVIDENCE**

If child has evidence of speciality work or assessment e.g., SALT/OT / CAMHS

they will **be put forward** for an SC assessment.

SENCO is Lead Professional

SENCO to explore If there are wider issues for the family if so then the school will be asked to seek advice from their ***Early Help link worker (EHLW)*** of local cluster

If no other worries put forward for SC assessment

Wider issues present in family

YES EHLW of local cluster in school offer advice SENCO to gather all SCD evidence BEFORE completing EHA send via EHITS

NO EHLW SENCO to gather all SCD evidence BEFORE completing EHA send via EHITS

No other issues in family SCD only issue ALL SCD evidence BEFORE completing EHA send via EHITS

ALLOCATED TO LOCAL CLUSTER

So whole family is supported with wider concerns by EHP

SENCO remains accountable for emerging SCD needs concerns

Put forward for SC assessment

Emerging Need Pathway - Families in category 2 will step down to the early help pathway:

- Early Help Practitioner SEND (EHPS) will contact the family and discuss the process for support and seek their consent to engage with early support
- EHPS start to identify a plan with the family, and start to undertake an EHA, this will be passed to the appropriate Early Years and Learning Cluster Team
- They will identify a lead professional from the child's local CC who will become the co-ordinator (LP) of the TAF

TAF HELD BY LP TO DISCUSS SC ASSESSMENT ROUTE

The TAF will meet regularly 6-12 weeks to review the plan (3 possible assessment decision can be made)

1 **SC assessment REJECTED** at review TAF held SCD not a concern other issues

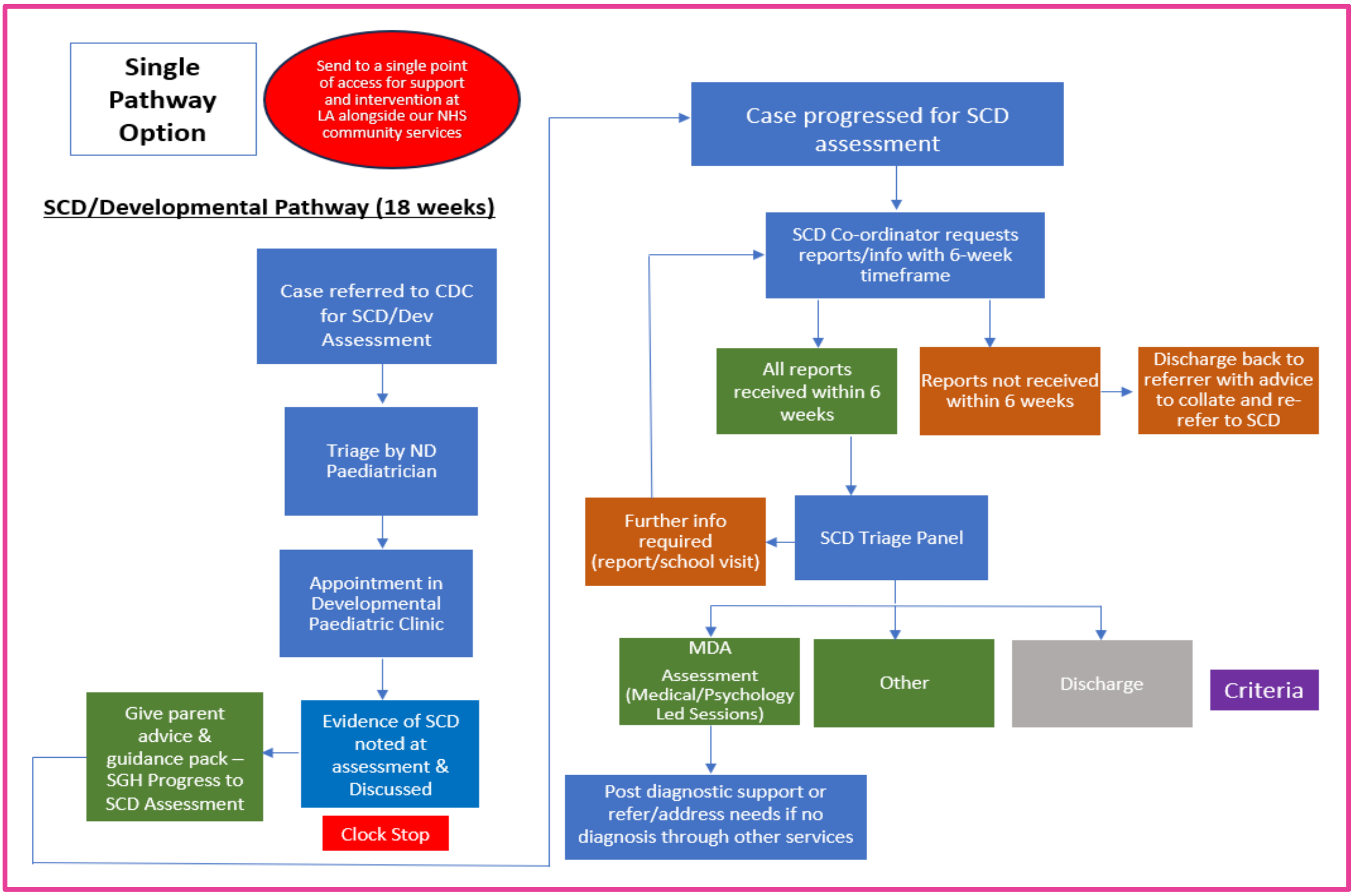
2 **SC assessment NOT agreed** at review TAF held by LP more exploring needed

3 **SC assessment AGREED** at review TAF held by LP appropriate services in the TAF will complete assessment forms and these will be part of the referral to the CDC requesting the assessment.

EHP stay active with family offering support from universal services

STEPPED UP DUE TO RISK

Social Communication Difficulties Pathway flowchart (Commencing September 2025)



9.4 Healthwatch Wandsworth Survey: Autism and mental health for children and young people

Healthwatch Wandsworth is your health and social care champion in Wandsworth. We are independent (not part of the NHS or local authority). You can find out more about us on our website:
https://www.healthwatchwandsworth.co.uk/
We are conducting a survey on the experiences of children, young people, and their carers with autism. This 20 question survey is anonymous. Healthwatch Wandsworth will hold your response data. This will only be kept for an anonymised report to the NHS and other relevant bodies. Please see the data privacy statement at the end of the survey for details on how we use your data. We may include quotes from you in our reports with any personal details removed.

We understand this is a difficult time for those seeking an autism diagnosis for their child due to lengthy delays. This research aims to take the views of local people to influence the changes of the autism diagnostic pathway and the support available for children, young people, and families with an autism diagnosis.

Note: In this survey, we refer to the 'autism diagnostic pathway.' This is the phrase we use to describe the process of seeking assessment and diagnosis from the NHS for autism spectrum condition.

About you

1. I am a

- ☐ Parent
- ☐ Another type of family member
- ☐ Paid support staff
- ☐ Other (please specify)

2. Which best describes your child?

- ☐ Waiting to get on the 0-8 year old autism diagnostic pathway
- ☐ Currently on the 0-8 year old autism diagnostic pathway
- ☐ Gone through the 0-8 year old autism diagnostic pathway
- ☐ On the over 8 year old autism diagnostic pathway
- ☐ Other (please specify)

3. Waiting for diagnosis

3. How long have you been/were you on the autism diagnostic pathway

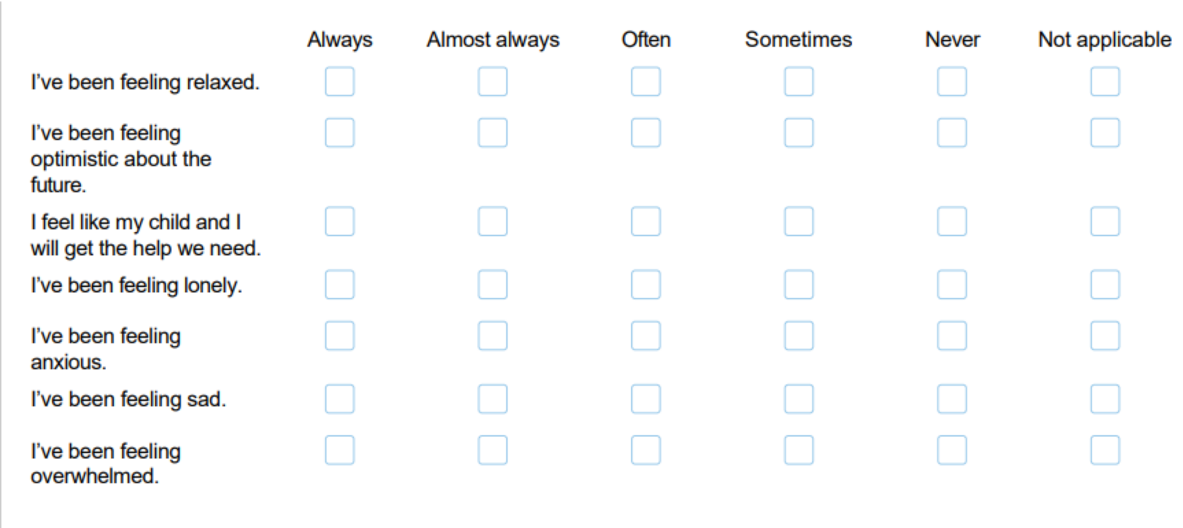
- ☐ Less than 6 months
- ☐ 6 month – 1 year
- ☐ 1 year – 2 years
- ☐ Over 2 years

4. Overall, how is/was the process of getting a diagnosis for your child?

- ☐ Very good
- ☐ Good
- ☐ Okay
- ☐ Poor
- ☐ Very poor
- ☐ Not applicable

Please tell us more about this experience:

5. Please describe your mental wellbeing as you wait(ed) on the autism diagnostic pathway



	Always	Almost always	Often	Sometimes	Never	Not applicable
I've been feeling relaxed.	☐	☐	☐	☐	☐	☐
I've been feeling optimistic about the future.	☐	☐	☐	☐	☐	☐
I feel like my child and I will get the help we need.	☐	☐	☐	☐	☐	☐
I've been feeling lonely.	☐	☐	☐	☐	☐	☐
I've been feeling anxious.	☐	☐	☐	☐	☐	☐
I've been feeling sad.	☐	☐	☐	☐	☐	☐
I've been feeling overwhelmed.	☐	☐	☐	☐	☐	☐

6. Please describe your child's mental wellbeing as they wait(ed) on the autism diagnostic pathway

	Always	Almost always	Often	Sometimes	Never	Not applicable
They've been feeling relaxed.	☐	☐	☐	☐	☐	☐
They've been feeling optimistic about the future.	☐	☐	☐	☐	☐	☐
They feel like they will get the help they need.	☐	☐	☐	☐	☐	☐
They've been feeling lonely.	☐	☐	☐	☐	☐	☐
They've been feeling anxious.	☐	☐	☐	☐	☐	☐
They've been feeling sad.	☐	☐	☐	☐	☐	☐
They've been feeling overwhelmed.	☐	☐	☐	☐	☐	☐

7. Do you have anything further to add about the impact of waiting for a diagnosis?

If you or your child are in distress, help is available.

You or your child can call Child Line at 0800 1111. They also have email, chat, and SignVideo available: https://www.childline.org.uk/getsupport/.
If you are in crisis, please call the 24/7 Mental Health Crisis Line at 0800 028 8000. You can also call Samaritans at 116 123.
If you are seeking counselling, please visit Wandsworth Talking Therapies: https://swlstg.nhs.uk/wandsworth-talking-therapies.

8. Are there any other conditions your child has been diagnosed with, or may potentially have? Please tick all that apply.

- ☐ ADHD/ADD

- ☐ OCD
- ☐ Dyslexia
- ☐ Anxiety
- ☐ Depression
- ☐ No
- ☐ Not applicable
- ☐ Other (please specify):

9. How could the diagnostic process for autism and the conditions in the question above be better coordinated?

10. What changes would improve the autism diagnostic pathway for you and your family?

4. Information and support

11. Have you received information about autism and support services from the following? Tick all that apply.

- ☐ NHS services
- ☐ Local authority services
- ☐ Wandsworth Autism Advisory Service
- ☐ Education settings (nursery, primary school, secondary school, etc.)
- ☐ Unsure
- ☐ No
- ☐ Not applicable
- ☐ Other (please specify):

12. How could the information provided be improved? (For example, what information would you like, how could it be made more accessible, what format would you like it in, where should it be circulated.)

13. The organisations in health, social care and education work together to support my child.

- ☐ Strongly agree
- ☐ Agree

- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Not applicable

If you would like more information about autism, please visit the National Autistic Society website: https://www.autism.org.uk/adviceandguidance/whatisautism.

14. Did your child access support through any of the following while you were waiting for a diagnosis. Please tick all that apply

- ☐ Speech and language therapy
- ☐ Psychologist
- ☐ Talking therapy
- ☐ Lego therapy
- ☐ Voluntary sector or charity support
- ☐ Occupational therapy
- ☐ Psychiatrist
- ☐ Drama therapy
- ☐ Play therapy
- ☐ Local authority support
- ☐ Unsure
- ☐ No
- ☐ Other (please specify):

15. Have you accessed support for yourself as your child waited/waits for an autism diagnosis

- ☐ Yes
- ☐ No
- ☐ Not applicable

What was the name of the support you accessed and what did it do?

16. Which supports have been helpful for you and your child, and why?

5. Demographics

It would be really helpful to know a little more about you and your child so that we can better understand how people's experiences may differ. These questions are completely voluntary.

17. How old is your child?

18. What is your child's gender identity?

- ☐ Girl
- ☐ Boy
- ☐ Non-binary
- ☐ Intersex
- ☐ Prefer not to say
- ☐ Prefer to self-describe:

19. What is your child's ethnicity?

- ☐ Arab
- ☐ Asian/Asian British: Bangladeshi
- ☐ Asian/Asian British: Indian

☐ Asian/Asian British: Pakistani
☐ Any other Asan/Asian British background
☐ Black/Black British: African
☐ Black/Black British: Caribbean
☐ Any other Black/Black British background
☐ Mixed/Multiple ethnic groups: Asian and White
☐ Mixed/Multiple ethnic groups: Black African and White
☐ Mixed/Multiple ethnic groups: Black Caribbean and White
☐ Any other Mixed/Multiple ethnic groups background
☐ White: British/English/Northern Irish/Scottish/Welsh
☐ White: Irish
☐ White: Gypsy, Traveller or Irish Traveller
☐ White: Roma
☐ Any other White background
☐ Any other ethnic group
☐ Prefer not to say

20. Which of the following best describes your family’s current financial status?

☐ I have enough for necessities, and at least a fair amount of disposable income that I can save or spend on leisure
☐ I have enough for basic necessities, and a small amount of disposable income that I can save or spend on leisure
☐ I only have enough for necessities
☐ I don’t have enough for necessities and I am getting into debt
☐ Don’t know/prefer not to say

6. Data and privacy notice

Information you provided us in this survey: We will anonymise the information you provided to help us in our role to obtain the views of local people to help improve health and social care services. Although we will never share your personal information with a third party, we may provide Wandsworth and Richmond Borough Councils, Healthwatch England, the NHS and other government bodies with summarised and anonymised information. Any information provided to us on this form will be used anonymously to help improve local health and social care services. Paper copies are stored in a locked cabinet at our offices. The information is also uploaded to and stored on the Smart Survey system online (password protected). View their privacy policy at https://www.smartsurvey.co.uk/privacypolicy. Data is downloaded and stored on our office server for the purpose of writing reports. Some of the data is uploaded to our CRM system and Healthwatch England will use the anonymised information for their national work. Your anonymised responses may be used in our reports and shared with local health and social care services or published on our website (see our privacy policy for more information). For more information about how we process and manage data see our privacy policy on our website or contact us to find out more.

21. If you would like to share more about your experience with us, please put your name and email address below. We will potentially reach out to you to do a case study.