Parents Experiences of Special Educational Needs and Disability Provision in Sandwell – March 2025

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Introduction

Healthwatch Sandwell (HWS) is the independent voice of the public in health and social care in Sandwell. HWS collect feedback from the public about their experiences of using health and social care services and use that feedback to work with service providers and commissioners to find ways to improve services. One of the ways that we collect feedback is to carry out projects that reflect the priorities of the public and that focus on particular services, conditions or parts of the community.

One of HWS priorities for 2024/25 is to focus on engaging with under represented groups in Sandwell. Through our engagement work with parents and carers of children with special educational needs and disabilities (SEND), we found that there are challenges with accessing health and care services for the support that is required.

National Context

A child or young person (0-25) is said to have SEND if they have a learning difficulty or disability which requires special educational provision to be made for them in order to support them to progress. Local service provision is governed by Part 3 of the Children and Families Act 2014 and the SEND Code of Practice 2015, although other legislation, such as the Equality Act 2010, is also relevant. The introduction of the Children and Families Act and SEND Code of Practice placed greater emphasis on the inclusion of children, young people, parents and carers in planning and decision-making, as well as on supporting aspirations and improving outcomes. This should be facilitated by strengthening joint planning and commissioning of services and the publication of a Local Offer, listing information about local SEND support.

The new Special Educational Needs and Disability Code of Practice is planned to play a vital role in underpinning the major reform programme.

For children and young people this means:

- Experiences will be of a system which is less confrontational and more efficient.
- SEND will be picked up at the earliest point with support routinely put in place quickly.
- Parents will know what services they can reasonably expect to be provided.
- Children and young people and their parents or carers will be fully involved in decisions about their support and what they want to achieve.
- Aspirations for children and young people will be raised through an increased focus on life outcomes, including employment and greater independence.
- Local authorities and local health partners have been working together to prepare for the new arrangements, to jointly plan and commission services for children and young people who have special educational needs or who are disabled. Those with more complex needs will have an integrated assessment and where appropriate a single Education, Health and Care plan (EHCP) for their support

The SEND Code of Practice 2014 and the Children and Families Act 2014 gives guidance to health and social care, education and local authorities to make sure that children and young people with SEND are properly supported.

If a child needs extra health and education support, an application can be made for an Education, Health and Care plan (EHC) to your local council.

A Sandwell Perspective

In Sandwell 17.4% of pupils have a statutory plan of special educational needs (statement or EHCP) or are receiving special educational needs support (previously school action and school action plus). This compares to an average of 19.4% across all English metropolitan boroughs. Note that these figures are for pupils attending state schools in Sandwell. They do not include children and young people for whom Sandwell is responsible but has placed out of the area.

In Sandwell, 13.9% of school-age children in need have a disability, compared to 11.3% in all English metropolitan boroughs.

Sandwell’s vision for children and young people in Sandwell with SEND is that they will be able to achieve their aspiration for a healthy, ordinary life through meaningful employment and fulfilling relationships within the community of their choosing. To help with achieving this vision the Local Authority has produced, as required by law, a 'Local Offer' which sets out the support they expect to be available for children and young people in Sandwell with SEND.

The Local Offer in Sandwell defines the areas of support that a child with SEND is entitled to:

- Education
- Money & Benefit
- Parents, Carers & Siblings Support
- Things for parents to do to support their children outside of school
- Social Care & Short Breaks
- Preparing for Adulthood
- Support Services
- Sandwell SEND Updates

Methodology

Information for the project was gathered by engaging with parents and carers of children with SEND, in group settings within schools and on a one-to-one basis at the place of the parent/carer choice. We asked a series of questions including:

- Has the child / children had a diagnosis or are they waiting for a diagnosis?
- Has the child been able to access an education and health care plan (EHCP) or are they waiting for an assessment?
- Is the EHCP reviewed and are the parents involved in the decision making around the assessment?
- What support is provided by the school and is the school meeting the child's needs?
- What are the experiences of Children and Adolescent in Mental Health Services (CAMHS), Special Educational Needs Co-ordinator support at school (SENCO) and SEND information and Advice Support Services (SENDIASS).
- What are the experiences of GP appointments, hospital appointments, etc?

Findings

One

My Son is 9 years old and is still waiting for and autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) assessment. He has been seen by two paediatric consultants who referred him in November 2023. We were told that there would be an 18 month wait but he was seen in June 2024 for an ADHD assessment. A draft education and health care plan (EHCP) was written in October 2024, but as of February 2025 we are still waiting for the draft so it can be reviewed.

Two

My son is 9 years old and has been diagnosed with attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD) and insomnia. He has been seen by a consultant, and I have been told that he may also have autism. He is currently at primary school; however, his education and health care plan (EHCP) has not been reviewed since 2022. I want my son to transition to a special educational needs school. However, if the EHCP is not put in place he cannot be considered for a special school. He is suffering from bad anxiety as he is not in the right school.

He is receiving support through the school case worker, but he needs additional support due to his behaviours that challenge due to his diagnosis. Our whole family are struggling due to his insomnia, he is keeping his brother awake.

He is being supported through the educational psychologist under early help, but the child and adolescent mental health service (CAMHS) seem reluctant to support him if he has a diagnosis of autism. We have been blamed for bad parenting. At one point in January 2025 his behaviour and anger were out of control, and we called CAMHS Crisis. We really wanted some help but the advice we were given was “take him for a bike ride”. The school have been brilliant in supporting his needs and have done several early years reviews, but we are still awaiting paperwork form SEND Information and Advice Services (SENDIASS).

Three

Our Son has an autism diagnosis and was being supported with his learning and needs at the Early Years and Child Development Centre based at Coneygre Early Years Centre, Tipton but has now been discharged. I think that our son also has command and demand disorder. The head of special needs at his school has been helpful and he has also been supported through Sandwell complex communication and autism team (CCAT) who have been helpful. He receives one to one support at the school but has a low immune system and is frequently off school with illness. He also has a very limited diet. He will eat no meat or vegetables and only limited dairy. The challenges we have are with our GP surgery, he is reluctant to go into the surgery due to fear and there are limited appointments available. I wished that our GP would be more flexible and understanding of his needs and would allow more time for him to adjust to go into medical settings.

Parent's Chronical

We met with a family of two boys, aged six and twelve, both have a diagnosis of autism, and both have an education and health care plan (EHCP) in place. The older child also has an attention deficit hyperactive disorder (ADHD) diagnosis and attends a mainstream School, where there is good special educational needs and disability (SEND) provision and a safe space for children with special needs.

The child aged six has been supported through a local family hub, Helping Hands, a support service for families with a child with autistic spectrum disorder (ASD) or attention deficit hyperactive disorder (ADHD). However, his behaviour has recently changed and has become challenging. We were told that appointments had been made with the GP but there were waiting times of over an hour causing distress for the child.

We were also informed that there had been an appointment at the Midland Metropolitan University Hospital, the parents told us that it was really difficult to find their way to the appointment, especially with a child with disabilities. There was no one to support, just a screen to log in. The family told us that there is now Paediatric support due to sensory issues to do with the textures of foods, this is causing weight loss.

We were told that a referral had been made to the child adolescent mental health service (CAMHS) for ADHD in January 2024.

The School had supported the referral and had supplied additional evidence. However, the family have been refused an assessment with no reason given. The parent went on to tell us that there is now an issue with insomnia and with behaviours that challenge, including stripping off clothing and physical aggression. Medication has been prescribed.

The family gave praise to Barnardo's who have supported with coping techniques and support with the EHCP plan as this needed to be updated. The family also said that the complex communication and autism team (CCAT) support within the school setting have been very professional, and they feel included and listened to.

This said, one parent is struggling with their mental health and required an increase in medication.

The family said that although their son and themselves as a family were getting some support, they were still anxious about the lack of communication from CAMHS and the stress of GP and hospital appointments.

Four

My Son is 9 and I have been told by Sandwell SEND Team that he has speech sound disorder and developmental language disorder. In May 2024 I received a letter to say I would be contacted shortly to arrange for my son to have an education and health care plan (EHCP) assessment. It has been 9 months and nothing has been arranged. My sons current Junior School has very little SEND provision and that they have informed me that he will be better supported once an EHCP has been put in place. When my son is at crisis at school he is moved to other classes and has challenges interacting with different children and staff.
The only other support we get is when he attends a school club twice a week for 15 minutes.
He had a speech and language therapy assessment in September 2023, but little support has been put in place. As he is getting older, he is becoming more and more frustrated and lashing out, we are concerned that we could be at risk due to this.

Five

We talked to a parent with two sons aged 5 and 7 years old. The older son had his education and health care plan (EHCP) in 2023 whilst the younger son has not got an EHCP in place. The younger son goes to a mainstream school whilst the older son is at a SEND school. Both sons have autism.

The parents told us that in December 2024 their youngest son went to the child adolescent mental health service (CAMHS) to go through his history and to put information together for an EHCP assessment. CAMHS were very good, as was the support through the SEND Information and Advice Services (SENDIASS). The educational psychologist has been very helpful. However, we were informed that the family are now waiting on a decision from the local authority to assess.

We were told that the School had suspended the youngest son several times for his behaviour which the parent said was out of frustration. However, CAMHS have helped him with a communication strategy and now he can express himself a lot better.

We were told that for oldest son the special educational needs co-ordinator (SENCO) at the school have been helpful but support for their youngest son is very limited.

The parents stated that the EHCP decision making process is far too long and not within the 20-week period as they had been advised.

We were also told that there is currently an issue with incontinent support for the older child. The parent explained that although they live in Sandwell the GP is in Birmingham and that Birmingham Trust should provide incontinent pull ups, but they have said that as the child is a Sandwell resident that Sandwell Trust should provide these. The parent told us that they have now been discharged from the service. She stated that nappies and pull ups available in shops are too small.

Parent's Chronical

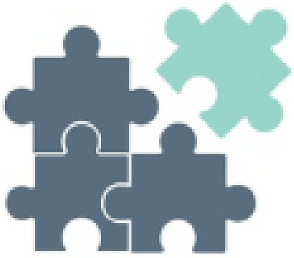
I have 2 sons both with special education needs and disabilities (SEND) and a daughter aged 5 showing SEND needs.

One of my son's has a learning age of 7 but is in year 10. His learning age does not seem to be improving. The child adolescent mental health service (CAMHS) have declined to support him as he is not on medication. He will be discharged once his multi agency meeting is completed with no extra help being put in place.

My son has learning difficulties, attention deficit hyperactivity disorder (ADHD), anxiety, dyslexia and sensory processing challenges. The school have been helpful and have asked for a meeting with the special educational needs co-ordinator (SENCO).

I can't get my other son into a SEND school as he has not had a full diagnosis. However, the school have started the process of an education and health care plan (EHCP). He was getting inclusion support, but we have been discharged from the service and handed over to the complex communication autism team (CCAT). We are still waiting for an autism assessment and have been told this will take up to three years which doesn't help with getting into a school which will best support his needs. We may consider a private assessment due to waiting times.

We have complained to CAMHS about the assessment waiting times for diagnosis. The special educational needs co-ordinator at school has been really supportive, but nothing seems to be moving forward.



My 5 year old daughter has been seen by two GP's who suspect she has autism, and a referral has been made to a paediatrician, but it has been turned down on two occasions.

My older son has very bad anxiety because he is incontinent during the night. He has been referred by the GP to Urology. We have asked our GP for help getting support for a bed mattress, but this has been turned down. This is really getting him down as he cannot have sleep overs or overnight school trip stays. CAMHS have refused to try other medication to help with this issue or his ADHD and once the multi-agency assessment is completed in March 2025, he will be discharged. We really need support, having three children with disabilities is hard.

Conclusion

Although there have been positive changes to service provision for children and young people with special education needs there are still frustrations and concerns from parents/carers:

- The lack of support from GP
- The long wait for assessment for diagnosis
- The difficulties getting an educational health care plan in place
- Communication from the child adolescent mental health service
- The differences in support offered within mainstream settings for children with special educational needs.

Next steps

- Share the experiences of parents and carers of children with special educational needs with appropriate stakeholders.

- Engage with parents/carers of children with special education needs from under-represented people, who are less likely to be heard by service professionals and decision-makers.

- Listen to the experiences of children and young people with special educational needs waiting for support.

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