

Information & Support | Influence & Change



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Community Support



Information Provision

Neurodiversity Referral in Shropshire- A summary Report

2025

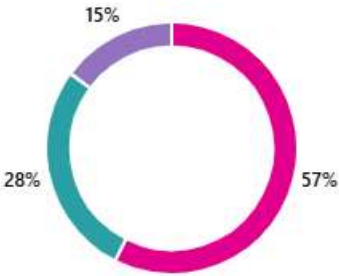
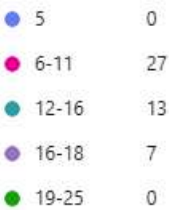


Parent Carers were asked to share their experiences of the Neurodiversity Referral and/or diagnostic Pathway in Shropshire. The following data is direct experiences that families have shared with us. Data has not been edited, and only names have been removed to ensure anonymity.

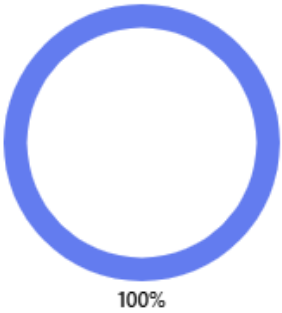
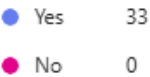
Neurodiversity Referral Survey

There were 47 responses from parents to this survey.

1) Age of Child/Young Person – The age range was between 6 and 18 years, with the most common age range being 6-11 years.

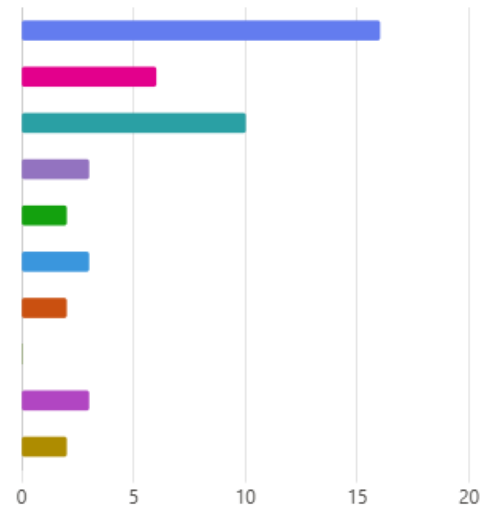


2) Do you pay tax to Shropshire Council?



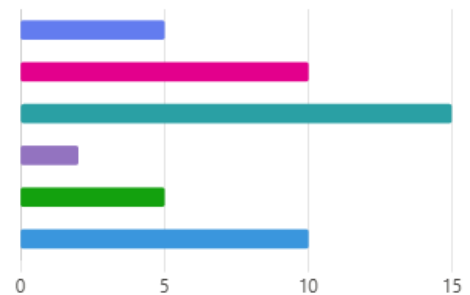
3) Type of Education Provision child/ young person attends

● Mainstream Primary School	16
● Specialist Primary School	6
● Mainstream Secondary School	10
● Specialist Secondary School	3
● Mainstream College/ Post-16 Provision	2
● Specialist College/ Post-16 Provision	3
● Home Schooled	2
● EOTAS	0
● Not in Education	3
● Other	2



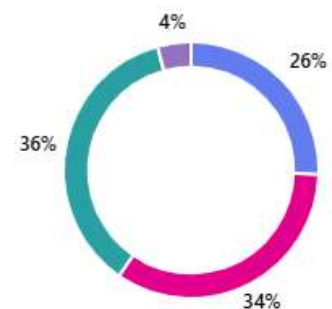
4) Please select which of the following apply

● A referral has been made - we have not had any communication	5
● A referral has been made and been rejected	10
● A referral has been made and been accepted	15
● A referral was made and a diagnosis was not given	2
● A referral was made and a diagnosis was given	5
● Other	10



5) Which of the following has your child/ young person's referral been made for?

● Autism (ASD)	12
● ADHD	16
● Autism and ADHD	17
● Unsure	2



6) When was the referral form sent?

Less than a year ago – 12 responses

1-2 years – 10 responses

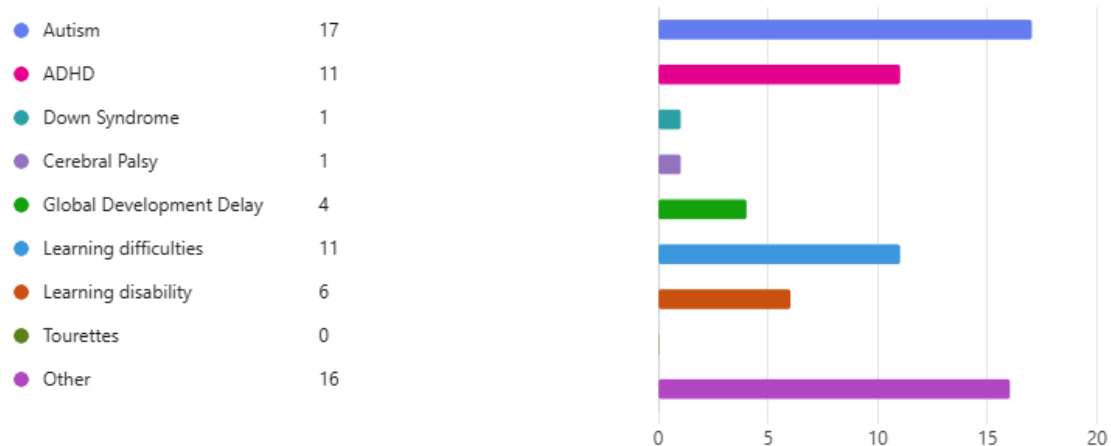
2-3 years – 6 responses

3+ years – 11 responses

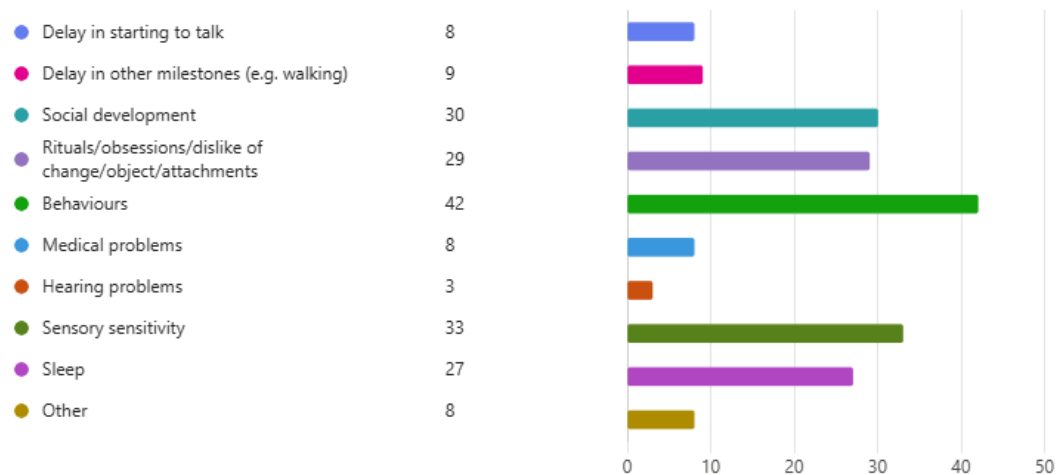
Unknown – 1 response

The oldest referral dated back to 2017, others reported there had been multiple referrals over the past 6 years.

7) Does your child/ young person have an existing diagnosis'?

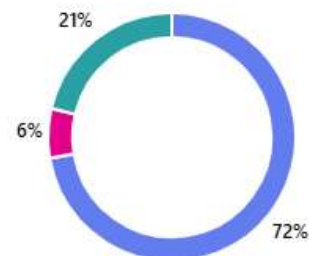


8) What was the nature of your initial concern? Select all that apply.



9) Were initial concerns raised by:

Parent Carer	34
Practitioner	3
Other	10



10) How would you rate your experience of the referral process for a ND assessment? (1- very poor to 5- very good)



Please note the 5* response to this question refers to a private assessment rather than BeeU. This makes the average rating **1.39**.

11) Please rate the following:



This can be seen in more detail below –

- a. The **overall** diagnostic process (referral to 1st appointment, duration of assessment, wait from assessment to final diagnosis)

Very Poor – 77.3%

Poor – 13.6%

Neutral – 6.8%

Very Good – 2.3%

- b. The information given to you at point of referral explaining the process

Very Poor – 76.6%

Poor – 8.5%

Neutral – 8.5%

Good – 4.3%

Very Good – 2.1%

- c. The Information given during waiting for assessment

Very Poor – 84.8%

Poor – 6.5%

Neutral – 6.5%

Good – 2.2%

- d. The information given at diagnosis

Very Poor – 62.5%

Poor – 9.4%

Neutral – 18.8%

Good – 9.4%

- 12) Is there anything you would like to share with us about the answers you have given above? Responses are grouped below –

Waiting Times

- The long waits and expectation that parents will just get by without help are horrible, there must be a better in term process to help.
- At the moment I can only comment on awaiting assessment. 2 years is excessive.
- We waited over a year and in the end paid for a private diagnosis.
- Still waiting to be seen! ASD diagnosis took 2 and a half years. No idea how long for his ADHD assessment. Simply not good enough.
- The ADHD assessment is still in the system, no indication on when this will be.
- Ridiculous wait. Also, some peoples children have therapy in the interim- not offered to us.
- Our referral has been accepted but we've only had that letter, the letter said the waiting time was 18 months plus.
- Paid private for autism assessment, took too long. Waiting for ADHD assessment, got taken off list by mistake - took several communications before said was a mistake and sorry.
- He was referred in September of year 7, it's going to be August of year 12 when he finally gets a diagnosis and medication.
- My initial referral was sent in June 2023... they sent a form to the GP asking for further Educational information, when the GP queried this and asked BEEU why it had been sent to them they told them it was just a copy and I had been sent the same form so it was just for their records! They did not send me the form so they just removed me from the list as I obvious hadn't responded... when I followed it up a few months later as I hadn't heard anything, they told me she had been removed off the waiting list due to me not providing the information and I pleaded with them explaining I couldn't possibly have responded to something that I knew nothing about 😞 They just said to go back to my GP and get re-referred but I had to wait another three weeks for an appointment and then it took over a week and a half for the paperwork to get sorted for me to sign 😞 I ended losing about five months of time on the already over two years waiting list! There was nothing they would do even though they admitted they sent the form to the wrong place... disgusting!
- Healios did my daughter's autism assessment and was diagnosed - this was quite quick and brilliant service. The ADHD assessment is still in the system no indication on when this will be. Mental health severely declining in the meantime. School refusal since November 2024.
- We are still waiting, for more than two years. Really poor service blamed on lack of provision.
- We had one appointment in June 2024 where they agreed to help but nothing since.

Communication

- There was no communication from BeeU. We reached crisis point with my son using a ligature and self harming.

- I am disappointed with the lack of communication from them. Even just a simple email or letter to say 'we haven't forgotten about you, the current waiting times are' would be appreciated.

Lack of Staff/Poorly Run Service

- I find the whole service is poor and overrun. We need more staff working for the service and providing assessment. As a result my children have struggled at the end of primary school and the start of secondary school.
- Absolutely abysmal service.
- Absolutely appalling service.
- My daughter was given an Autism diagnosis by BeeU in 2022 and is now awaiting treatment for ADHD; the deterioration in the quality of “service” provided in the last three years is unbelievable, ie BeeU is not providing us with any meaningful service.

Refusal to Assess

- 4 referrals done and all been rejected even when a consultant has been involved up until 5 years of age.
- My son was not accepted onto the pathway, there was no explanation/follow up for this. My son continues to display what looks like ADHD symptoms. The only explanation I was given was that he has trauma. No follow up and no one I could speak to. I am aware that someone who has trauma should not be declined an assessment purely on this. He is missing out on potential support due to this.
- We ended up paying privately and they said he was clear and easy to diagnose; this is after TWO referrals once at primary and once at secondary and both dismissed as “not struggling to access education” despite having SEMH struggles.
- Our child was rejected for an assessment because he is adopted.
- Didn't even wait for school assessment report which conclusively showed they should see her and it was rejected before seeing this evidence.
- Very poor because denied access due to beeU saying they don't recognise the diagnosis the CDC gave him.
- They do not accept home educated children. I feel this is discrimination.
- We had already paid for a private consultation with a specialist. They had confirmed ADHD and ASD and a PDA profile based on information from parents and school, plus previous medical reports.
- Rejected referral to assess . Had to pay private and get the diagnosis which the Consulatnt agreed was obvious and was horrified BEEU rejected to assess after reading school submitted paperwork. Referral rejected as BEEU state no school evidence yet it was school who referred. No logic at all.

Other

- The parents are left struggling to cope but seen as a good option then you end up struggling with your own mental health.
- Parents aren't able to make referrals and there is a small list of people who can, which restricts the ability to get support.

- A diagnosis was not made by BeeU - it was confirmed from a private referral process.
- After diagnosis you get nothing but medication. Referrals for anything else have been so far impossible to get but no questions on here about that.
- The hardest part was getting inexperienced teachers /GPs to support the process. Once diagnosed I was told “he is one of the most severe ADHD cases I’ve diagnosed”. The teachers and GOs, health visitors, family support workers dismissed me.
- Girls mask so school don't always see the problems that the parents experience yet you only use the evidence of the school.
- His special school let him down. He left last summer with chronic anxiety and has barely left the house since. Been told he needs to self refer to IAPT but he can't manage that and they won't let me do it for him. GP has made urgent referral back to BEEU as they can't do anything.

13) Were you offered an assessment with Healios?



14) If you answered yes to the above, but you did not accept a Healios assessment, please could you provide feedback of why you made this decision

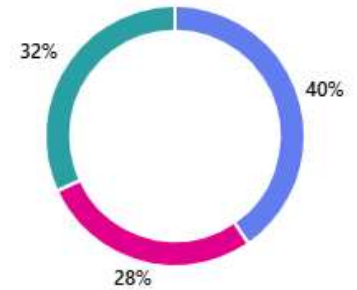
- Never heard of it
- She could not do an assessment on line
- He could not cope with online interaction
- He could not manage online

15) How long since the referral was accepted have you been waiting or did you wait for assessment?



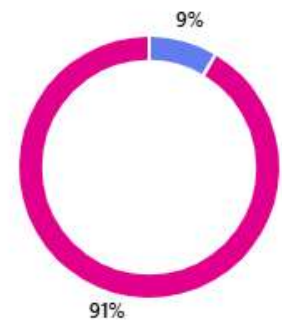
16) Were you / school / GP asked to provide additional information **before** your referral was accepted on to the waiting list?

● Yes	19
● No	13
● Unsure	15



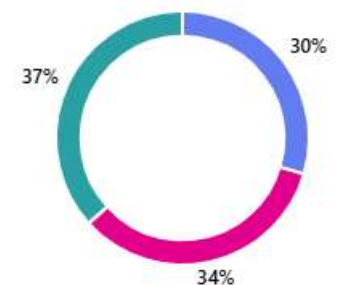
17) Do you feel you were kept updated about the waiting list and how long your child/ young persons wait for assessment would be?

● Yes	4
● No	43



18) Did the wait for assessment have a negative impact on:

● Yourself (Parent Carer)	29
● Your child/ young person	33
● Your family	36



19) Is there anything you would like to share with us about the answer you have given above? Responses to this question are grouped below –

Refusal to Assess/Rejection

- Rejection number 4 has just been received and asking for examples of observations from professionals when they know he's been homeschooling since 2023 and have got previous examples, but have been refused. He also has EHCP which has been refused.
- Re assessed for mental health (rejected) as behaviours and mood worsening. No support given.

- We have made at least four referrals for our child - the first when he was aged 6. He has been rejected each time because he is adopted, though his sensory/social issues have not changed, despite years of psychotherapy.
- Got refused twice from doctors and school referring so I find the whole situation bad, my child should of been given access to support

Waiting Times

- It is so frustrating the lost time whilst waiting.
- Unable to meet need as needs not identified quickly enough / not been assessed. Impacts the child's mental health significantly.
- Not diagnosing her earlier meant a delay in services, delay in school offering support, delay in her dealing with her diagnosis and ultimately lead to her recurring a diagnosis during the onset of puberty and transition to high school meaning her mental health suffered enormously.
- Still waiting - on a two year list.
- Child is not really aware of referral yet. But for parents this feels like it sits over us for a long time.
- In the end we didn't think we would be seen before the move from secondary education to college so we paid for a private assessment.
- The wait is dangerous not only for my neurodiverse daughter, but also for my two other children and us as parents. The fact that my daughter has been left untreated for so long constitutes institutional neglect.
- It's been nearly 6 years.
- I am still waiting and have had no update as to whether he is still on the list or whether he has gone up the queue.
- We have been waiting for some support and we feel other children have come before ours. I think boys are very prioritised because of their behaviour and girls are left to suffer, like our twins.

Lack of Support

- Very little help or support, what was provided made no difference at all.
- There does not seem to be any 'waiting well' support other than a few suggested weblinks on the back of his acceptance for referral letter. When we got the date in May 2024 I was told on the phone by a member of staff that it was an ADHD assessment. When we got there it turned out to be an initial assessment. The people who did the assessment said if we had put our referral in the month before we would have skipped this stage entirely (not helpful). They said they would call us to talk through their findings and recommendations. They never called. When we finally got a letter it just said he had been accepted on to the neurodevelopmental pathway. I had to call to clarify if they were going to assess him for ADHD, Autism or both. The whole process is frustrating and impersonal.
- Need to be in term support.

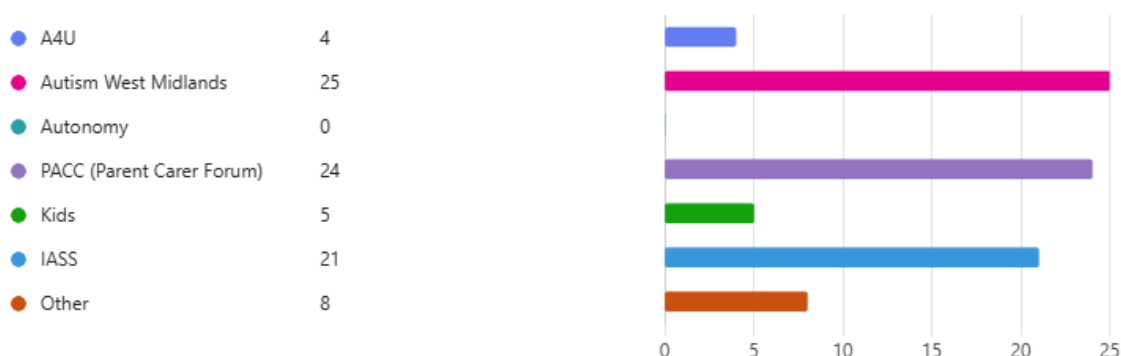
Impact on Families/Children

- It affects the whole family and is an emotional roller coaster for the whole family.
- Huge impact on our family life, his school work and attendance.
- Just absolutely awful. Really not fair on the children and their education.
- The Trauma and loss of Education and Childhood that this broken system has caused is heartbreaking... Our lives have been ruined and even though an EHCNA is now only just been agreed by the School to be submitted I have heard that the LA are going way over the Legal Timeframes as they are overwhelmed by the amount of applications and so are delaying them as much as possible! Shropshire Services are failing our Children and the Families they have to try and manage these vulnerable SEN Children and no wonder there's a Mental Health Crisis amongst Youngsters because Needs are not being met! It doesn't take a rocket scientist to work out why... The system is just no longer fit for purpose and it's all just so broken.

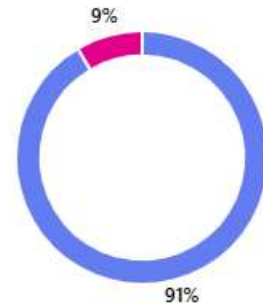
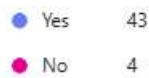
Other

- BeeU don't consider the impact their failings have. The process and system is terrible and does not do anything to support families during the process.
- Communication is ridiculously poor.
- BeeU abused our son in a sitting with the practitioner and mocked his struggles.

20) Have you accessed support from any of the following charities/ organisations?



21) If appropriate, PACC are able to raise cases on an individual basis with practitioners. Do you give your consent for your feedback to be discussed with practitioners?



22) PACC offer a Navigator service, where a member of staff with lived and work experience of the system is able to talk to you to help you navigate your child/ young persons journey. Initial contact will be a call or teams meeting.

A navigator may also be able to speak to a practitioner at BeeU to provide an update on your child/ young persons referral.

If you would like a member of staff to get in touch, please leave your email address below – 96% responded yes they would like this, 4% said no.

Summary

- **57%** of responses had children between the ages of **12-16 years**.
- In terms of education provision, **34%** of responses attended **mainstream primary** schools and **21%** attended **mainstream secondary** schools.
- **32%** of responses had made a referral and been **accepted to BeeU**, **21%** had made a referral and been **rejected**.
- **36%** of referrals were for **autism and ADHD**, **34%** **ADHD** and **26%** **Autism**.
- **30%** of referrals were made **less than a year** ago, **28%** were made **over 3 years** ago and **25%** were made between **1 and 2 years** ago.
- **25%** of referrals have an existing diagnosis of **Autism**.
- Regarding the nature of the initial concern, **21%** were for **behaviours**, **17%** **sensory sensitivity** and **15%** **social development**.
- **72%** of initial concerns were made by **parents**.
- 72% rated the referral process for a ND assessment as **very poor**.
- The majority of issues relate to **waiting times**.
- **87%** were **not** offered an assessment with **Healios**
- Once a referral is accepted, **38%** have been **waiting 1-2 years** for an assessment.
- **40%** of respondents were asked to **provide information before** being accepted on to the waiting list.
- **91%** were **not kept updated** about the waiting list and timescales for assessment.
- **37%** report the wait had a **negative** impact on their **family**, **34%** on the **young person** and **30%** on the **parent carer**.
- **Waiting times** and **refusal to assess** were key comments from respondents.

- **29%** have accessed support from **Autism West Midlands**, **28%** from **PACC** and **24%** from **IASS**.