



SNAP PARENT CARER FORUM

CENTRAL BEDFORDSHIRE

Position Statement

Waiting times to access an autism and/or ADHD Assessment

SNAP PCF role.

SNAP (Special Needs Action Panel) is a pro-active, independent forum of parent carers who all have children and young people with Special Educational Needs and/or Disabilities (SEND). As members of the National Network of Parent Carer Forums, we support the development of parent carer participation, a process in which parents work together with professionals to make improvements to local services. SNAP PCF act as a conduit for a wide variety of local professionals in their work with children and young people with SEND. SNAP's purpose is to improve the services provided for young people who are aged from 0-25 years old.

Position Statements.

SNAP PCF will be publishing position statements as and when the need arises for our Forum to formally communicate our point of view on any issues that arise. These can be found on our [website](#).

The Issue.

Waiting times for children and young people in Central Bedfordshire to access health services for an autism or ADHD diagnosis have continued to increase at an alarming rate. Long waiting times have become the norm, expected and explained away.

SNAP PCF have written this report to analyse the reasons and effects of waiting times in a challenging landscape and there are no easy answers to fix a broken problem. It aims to explain the complexities involved in obtaining the right timely support for children and young people in Central Bedfordshire. The waiting times encountered can pose challenges for families.

The waiting times cited in this report relate to Bedfordshire Community Health Services (BCHS), which manages the Edwin Lobo Centre in Luton and the Child Development Centre in Bedford. (Central Bedfordshire does not have their own centre). They assess autism in

children aged 0 to 12 and ADHD in those aged 6 to 17. The waiting times for autism assessments in individuals 14 and older, refer to child and adult mental health service (CAMHS) as they undertake autism assessments for this age group.

The National Institute for Health and Care Excellence (NICE) guidance [states](#) that people with suspected autism should have a diagnostic assessment started within three months of their referral, so that appropriate health and social care interventions and support can be given.

According to the Darzi Report

“The problems faced by all NHS patients are similarly encountered by children and young people. At the moment, too many are being let down. Childhood is precious because it is brief; too many children are spending too much of it waiting for care. It is apparent that the NHS must do better and that national policymaking on care for children and young people needs to be more joined up.”

A recent Freedom of Information request to Bedfordshire Community Health Services by the Central Bedfordshire SEND Action Group has shown just how desperate things are becoming.



The waiting times are for children and young people in Bedford, Luton and Central Bedfordshire combined. 120 weeks is over 27 months nowhere near the 3 months that NICE guidance states and 130 weeks is nearly 30 months which is 27 months over NICE guidelines!

A report by the Children’s Commissioner published in November 2024 ‘Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions’ states the following.

“We have created a system which is working against itself. Forcing children and families to jump through endless hoops to get the help they need has huge knock-on effects for the capacity of statutory services, which are often the last resort. It is shocking to me just how

many providers have published apology messages and videos about the long waits for their neurodevelopmental assessment pathways.”

On the Bedfordshire Community Health Services website you can view a video from the Service Director apologising for the waiting times in Children’s Paediatric Services [Bedfordshire and Luton Community Paediatrics waiting times](#) and explaining the changes they are making to offer support whilst they wait.

SNAP PCF has been informed.

“There is a focus of support alongside diagnosis, a new approach is being trialled called the Early Concerns Neurodevelopmental Pathway which is led by a new team including specialists from health and education to work with schools and families to put support in place to support children’s needs. This is the first step, and only once a family has gone through this process and further support is required the Specialist Support Team will enable access to a diagnostic assessment. Bedfordshire is moving to a ‘needs-led, rather than a ‘diagnosis-led’ system to help manage waiting times and try to offer support whilst waiting. Parents need a clarity what this means for their child or young person.”

SNAP PCF would ask that an update is provided to explain how the Early Concerns Pilot is being monitored for impact and communicated to parent carers.

Information from Bedfordshire Community Health Services about the changes made to support the waiting times

- *“All new patients that are accepted to our service are invited to attend or view an early intervention workshop. This workshop is an extremely valuable resource where the nature of our service will be explained. You will also find out how to obtain the support your child needs whilst you are waiting for an appointment.*
- *Information about waiting times has been added to letters and community resources. This includes information about where to seek local support.*
- *We are working with schools to develop an Early Concerns model of working to ensure children access support as soon as possible after their needs are identified.*
- *The service meets monthly with Parent Carer Forums to listen to feedback and share updates.*
- *The service hosted SEND Health Focus Week. This was a week of engaging and informative workshops for parents and professionals to support children with SEN disabilities. This was done in partnership with parent carer forums and CAMHS.”*

The report by the Children’s Commissioner also mentions.

“Services have not been resourced to keep pace with the increasing need for assessment and support for children with neurodevelopmental conditions, such as autism and ADHD.

There are hundreds of thousands of children and young people in England who have a neurodevelopmental condition or several co-occurring neurodevelopmental conditions which require(s) support. Neurodevelopmental conditions include autism, ADHD (Attention Deficit Hyperactivity Disorder), and disorders affecting communication, mobility, and learning.

The average wait time from referral to a diagnosis of autism in community health services is 2 years 2 months, compared to 1 year 5 months in mental health services. The average wait time from referral to a diagnosis of ADHD in community health services is 2 years 5 months, compared to 1 year 7 months in mental health services.”

We asked CAMH what their waiting times are and have been advised the following.

“Please see data and commentary below of current wait times for first appointment for each locality.

<i>Bedford</i>	<i>224 young people</i>
<i>Central Beds</i>	<i>304 young people</i>
<i>Luton</i>	<i>140 young people</i>
<i>Out of area</i>	<i>3 young people</i>
<i><u>Total</u></i>	<i><u>671 young people</u></i>

The length of time between last assessment appointment and feedback session is between 1 to 2 weeks. Current waiting time is around 16 months. It was 22 months in October 2023”.

Again, we can see this is above the NICE Guidance of three months waiting times.

Bedford Borough Council had their area SEND Inspection during November 2024, in the report health services were given an area for improvement.

“Some children and young people with SEND wait too long for neurodevelopmental assessment in Bedford Borough. The partnership has a limited oversight of how long these children are waiting. The partnership should improve how it uses information and data to work collaboratively to reduce the delays in neurodevelopmental assessments that some children and young people currently face.”

The myth of needing a diagnosis before you can get support.

What IPSEA tells us

“A child does not need a formal diagnosis to receive support in school. Support should be available based on the child’s needs. The relevant issue is the difficulties and challenges a child faces, which do not change if and when a diagnosis is given.

However, without an appropriate professional assessing what the individual needs of a child or young person are, it can be difficult for school teachers and college tutors to know what educational support they should be offering – and too easy for the needs of children and young people to be denied or ignored.

Neither the definition of ‘special educational needs’ under section 20 of the Children and Families Act 2014 nor the definition of ‘disability’ under section 6 of the Equality Act 2010 requires a specific diagnosis. This is just as well, given that the underlying cause of an individual child or young person’s difficulties or impairments might not ever be known.”

Yet we know from the [2023 SEND Data Dashboard](#) that was taken to the SEND Overview and Scrutiny Board in May 2024.

The data showed for school suspensions.

*“% suspensions for pupils with SEND Support Education November 2023 Annually Snapshot
16.45%*

*% suspensions for pupils with an EHCP Education November 2023 Annually Snapshot
20.22%”*

Part time timetables.

The Central Bedfordshire SEND Action Group freedom of Information Request to Central Bedfordshire Council in February 2025 showed that there are 356 children on Part Time timetables with over 200 of these children and young people over 200 have an Education Health and Care Plan (EHCP).

How many children and young people are on a waiting list for a diagnosis and without this diagnosis are either being excluded, on a part-time-timetable or their parents are being fined and prosecuted for not attending school, or come under [Emotionally Based School Non Attendance \(EBSNA\)](#)?

Parent quotes.

“Personally, for us a diagnosis did not make a difference as to how we viewed or treated our daughter as we had all accepted it and made allowances where necessary. However, it was important to get one to make sure that she got the right support at school and for her to be able to advocate for herself at university next year and in the future with work. She is more accepting of who she is and realises why she needs a rest after "too much socialising,” and she has difficulty following instructions.

Diagnosis leads to understanding and to a better experience for the Young Person. 20 months is too long and can have a major impact on somebody's mental health if they feel like they do not belong or questioning if something is "wrong" with them. Especially if a parent or teacher does not support and adjust their behaviour and if they do not have the right friendship group who accept them for who they are. Thankfully, our daughter had

the right family support and peer support and "found her tribe" at school during the process.

Our YP should not be at the mercy of luck, they need better and quicker diagnosis."

Right to Choose.

The [NHS Website](#) provided the following information.

"What is Right to Choose?

In England, under the NHS, you now have a legal right to choose your mental healthcare provider, including for Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) assessments. This service, offered through the NHS, is free of charge.

Introduction to Right to Choose Referrals

Did you know that NHS patients have the legal right to select their mental healthcare provider? This important right allows you to explore alternative providers if the waiting time for an ADHD or ASD assessment is too long. Right to Choose, introduced in 2018, is still a relatively new system, and many patients may not be aware of these options.

Who Can Offer Right to Choose Assessments?

Several clinics across the UK offer Right to Choose ADHD and/or ASD assessments. To be eligible to provide this service, clinics must also offer the same service to the NHS in England. Private-only clinics are not eligible. Checking a provider's website is a good way to determine if they offer the services you need.

Which Providers Offer Right to Choose Assessments?

The list of clinics offering Right to Choose assessments is constantly evolving. Currently, several clinics are available, but there may be other providers worth researching as well.

Important Resources

- *ADHD & Right to Choose referrals: [Visit the ADHD website for more information.](#)*
- *ASD & Right to Choose referrals: [Visit the National Autistic Society website for helpful details.](#)*

Things to Consider About Right to Choose

It is important to note that many clinics offering these assessments can diagnose ADHD or ASD but may not provide medication titration. This means you might need a local NHS referral if medication is required to manage symptoms."

The Bedfordshire, Milton Keynes, Luton Integrated Care Board (BMLK ICB) have told SNAP PCF

"Right to Choose (RTC) is for the diagnostic assessment only therefore any ongoing treatment would be via BLMK ICB NHS commissioned providers, or parent's choice to

purchase privately. Therefore, there may be a delay if the RTC assessment indicates medication as a treatment option and the medication being prescribed. Cambridge Community Services (CCS) would typically lead on the prescribing and titrating of any medications and subsequent annual reviews; primary care would support with repeat ongoing prescriptions.”

Other areas of concern.

Delays to ADHD medicine is another hurdle parent carers are having to manage [Bedfordshire Community Services website](#) provides the following information

“Key Points:

- *The ADHD medication shortage is ongoing and could affect medications and strengths at any time.*
- *If your child or young person is already on medication, continue with your current prescription unless advised to change by your doctor.*
- *New patients may face delays in starting medication due to supply issues.*
- *The situation can change quickly.”*

SNAP PCF – How we are trying to support our membership.

We know from the feedback we receive from parent carers that whilst waiting for an appointment for a autism or ADHD diagnosis is really stressful, there is a term used by professionals called ‘waiting well’ we understand this means in reality ‘what is the worst a parent can tolerate’. We understand the lack of resources into the SEND system as a whole has created the many challenges we now are experiencing. We influence at a national level through feeding into the [National Network of Parent Carer Forums \(NNPCF\)](#). They work directly with the Department for Education and NHS England.

At a local level SNAP PCF meet with Bedfordshire Community Health Services and CAMH to talk about the key issues and concerns shared by local parent carers. One of the biggest concerns that SNAP PCF continues to raise is how long families are having to wait for a first appointment and to move forward with the right support for their child or young person.

Together, we been working on ways to try and ensure families feel supported while they are waiting. This includes making sure schools are kept informed, so they can start putting the right support in place for the child without having to wait for a formal diagnosis.

We have worked with Bedfordshire Community Health Services to create resources like the [Diagnostic Support Pack](#). We have also worked to develop an early support workshop for parents whose children are on waiting lists, so families can get guidance and help from the start.

The BMLK ICB commissioned SNAP PCF to localise a book to Central Bedfordshire to provide information to parent carers ‘Supporting your Neurodiverse Child/Young Person.’ This is a free digital download which can be found on [our website](#) we have had some amazing feedback about this resource from teachers and parent carers and over 1600 downloads so far, we were also funded to print hard copies of the book too which we have distributed at events,

Central Bedfordshire has is now included in the Partnership for Inclusion in Schools Project, better known as [The PINS Project](#)

“Partnerships for Inclusion of Neurodiversity in Schools (PINS) will bring health and education specialists and expert parent carers into mainstream primary settings to:

- ***help shape whole school SEND provision.***
- ***provide early interventions at a school level.***
- ***upskill school staff.***
- ***support strengthening of partnerships between schools and parent carers.***

The Partnerships for Inclusion of Neurodiversity in Schools project is testing a new model for supporting good outcomes in mainstream schools for Neurodiverse students and strength parent carer and school partnerships. The project will focus on strengthening knowledge, skills and improving environments to better meet the needs of neurodiverse children. Through a focus on supportive learning environments and well-equipped schools we can improve the outcomes for this group of children.”

SNAP PCF is excited about using the lived experiences of parents to feed into this project, meeting new parents, and building those vital relationships to help bring about holistic support in schools.

Through Central Bedfordshire being part of the [SEND and Alternative Provision Change Programme](#) we have received additional funding to recruit a part-time engagement officer, this has enabled us to create the SEND Roadshows which bring together education, health, social care and local organisations to provide information, support and guidance to parent carers, we have done this as we know how difficult it can be to meet professionals in person, to have a conversation in an informal way. These Roadshows have been extremely popular with both parents and professionals who have appreciated the opportunity of having all services together under one roof to talk to, every parent carer asked,

“Would you recommend SNAP PCF Roadshows to a friend?” said “YES!”

We have also been able to fund free training with [Add-Vance](#) and Sensory Processing training with [Blossom Occupational Therapy](#)

We have also taken on the [Healthy Parent Carer Programme](#) which is a 12 week programme to offer support in improving parent wellbeing. We have run this twice now and have received such positive feedback from parents who have appreciated time to focus on themselves, one parent said,

“HPC Course – I would do it forever!”

SNAP PCF works hard to try and make a positive difference to our SEND community, as parents ourselves we know the struggles, fights and sheer desperation parent carers must sometimes endure.

We have secured additional funding to support parent carers. Our primary role is to provide strategic guidance, rather than offering training, workshops, events, or resources. However, we recognise the necessity for these services. Parents are crying out for support, for someone to see them, hear them and understand their struggles which is why we are so passionate to do everything we can to stand by the side of our parents. We have an amazing SEND community in Central Bedfordshire; we look out for each other and try to offer hope and advice too. SNAP PCF are, however, only as good as the parents who join us provide their feedback, as we only know what is going on if they tell us and get involved with SNAP Parent Carer Forum.

If you want to find out more about us, please see our website www.snappcf.org.uk

Bedfordshire Community Health Services Response to our report.

“We understand how frustrating it is for families waiting for a diagnosis. In common with services across the country, we have seen a large increase in the number of children being referred for an autism and/or ADHD assessment, sadly this has meant longer waits for families. Long waits are associated with Children who need to see a Paediatrician.

Access to support in the community (including the Community Paediatric service) is available and we encourage children and families to try supporting strategies offered through our early intervention offers.

We are working hard to reduce wait times to see a Paediatrician and alongside these efforts we are also looking at how we can best support children. As a result of this, we are piloting a new service offer in some education settings for children with suspected Neuro-developmental concerns in Central Bedfordshire, offering support strategies at the point of need. This takes the form of a tool kit completed with people who know each child and offering support strategies in real time. This means that we will provide support early as well as developing key insights into the needs of each child. If required the diagnostic pathway is available thereafter, access to the diagnostic pathway is via a dedicated team of health and Local Authority colleagues.

We have been co-producing an update on 'what to expect from a request for support to the Community Paediatric service' which is attached below.



For all families, this will be:



The support package will include:

- Support and advice based on their individual needs, including within their education setting
- An invite to drop-in sessions
- Additional specialist assessments
- Blood pressure and growth monitoring

The young person may also be booked to see a paediatrician for a specialist assessment. Not all young people referred to us will need to see a paediatrician for their needs to be met. The service also offers:



This process allows us to ensure all families receive support more quickly and that support is more closely targeted to individual needs.

For help and support while you wait, visit our Neurodiversity Support Pack on our website by clicking [here](#) or scanning the QR code.



For further support and updates on our service offers please see following link:

<https://bedslutonchildrenshealth.nhs.uk/services/bedfordshire-and-luton-community-paediatrics/>

SNAP PCF Recommendations

- An update to explain how the Early Concerns Pilot is being monitored and communicated to parents.
- To publish the data of how many children and young people are on a waiting list for a diagnosis and to know without this diagnosis are either being excluded, on a part-time-timetable or their parents are being fined and prosecuted for not attending school, or are [Emotionally Based School Non-Attendance \(EBSNA\)](#).
- An information session with Bedfordshire Community Health Services for parent carers in Central Bedfordshire about waiting times, pathways, and support.
- Bedfordshire is moving to a 'needs-led, rather than a 'diagnosis-led' system to help manage waiting times and try to offer support whilst waiting. Parents need a clarity what this means for their child or young person.
- Create a separate tile on the Local Offer for Neurodiversity.
- Create a myth busting webpage for Bedfordshire Community Health website

Information for parent carers of where to find support.

- Bedfordshire Community Health Services [Bedfordshire and Luton Community Paediatrics waiting times](#)
- Bedfordshire Community Health Services [Neurodiversity Support Pack](#)
- LO video pathway [Luton and Bedfordshire's Neurodevelopmental Disorder \(NDD\) Pathway | Central Bedfordshire SEND Local Offer](#)
- Neurodiversity Support Pack [Neurodiversity support](#)
- Our book [Supporting Your Neurodiverse Child/Young Person - SNAP PCF - Central Bedfordshire](#)
- Central Bedfordshire Local Offer Pathological Demand avoidance [Pathological Demand Avoidance \(PDA\) Position Statement | Central Bedfordshire SEND Local Offer](#) and PDA Position Statement [cbc_pda_positon_statement.pdf](#)
- Autism Bedfordshire offers support and training [Training & Consultancy » Autism Bedfordshire](#)
- A parents guide to the Graduated Approach [The Graduated Approach: A Guide for Parents and Carers | Central Bedfordshire SEND Local Offer](#)
- Central Bedfordshire Local Offer Website [Emotional Health and Wellbeing Support for Children and Young People](#)

- ADHD Right to Choose [Right to Choose - ADHD UK](#)
- IPSEA [The myth of needing a diagnosis before you can get support](#)

Please stay connected with us by following us on Facebook, emailing us updates on your lived experience, completing our surveys and attending our events.

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