

ADHD Support Feedback

Service User Experience Evaluation

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Introduction

The Cambridgeshire and Peterborough Integrated Care Board (ICB/CPICB) want to understand the perceptions of local people who have either: had a diagnosis of Attention Deficit Hyperactive Disorder (ADHD), think they may have ADHD but aren't currently on a National Health Service (NHS) waitlist, or people who are on an NHS waiting list for the ADHD clinic, regarding what support should be available for people in these groups.

The SUN Network are an organisation whose objective is to hear the voices of individuals with lived experience of mental health and/or drug and alcohol challenges across Cambridgeshire and Peterborough, and ensure that those voices are influencing and shaping service provision, locally.

Nationally, there is a lack of wrap around care for people who are living with ADHD or think they may be, alongside very long waitlists for a diagnosis. This is due to an increase in numbers of people trying to access the NHS ADHD service and get a diagnosis. The CPICB want to hear the views of local people in order to propose an informed pathway of care for people who may or may not have a diagnosis of ADHD and ensure that any support that could be available is informed by people with lived experience. The SUN Network helps to provide that perspective.

Methodology

The SUN Network designed a short survey with the input of the ICB, to create a framework allowing people to feedback about their experiences about support for ADHD. The SUN Network have had face to face/online conversations with people who would like to share their experiences, however a questionnaire was designed to allow people to fill in a survey online. The survey has been shared with the Cambridgeshire and Peterborough ADHD Clinic, on SUN Network's social media channels and with the RCE Wellbeing Hub who have distributed it to their students.

Two responses have been recorded online, therefore the remaining respondents qualitative feedback has been paraphrased and edited to maintain anonymity but accurately reflect feedback that has been given. It is important to note that not every person filled in a survey, some of the feedback was gained from general conversation surrounding the questions, therefore not all the graphs will represent the entirety of the participants' feedback.

The SUN Network will continue to obtain people's feedback and ask people if they would like to be involved in a working group to design what a pathway could look like.

A copy of the questionnaire can be found in the appendix.

Demographics

Table 1. Gender of Respondents

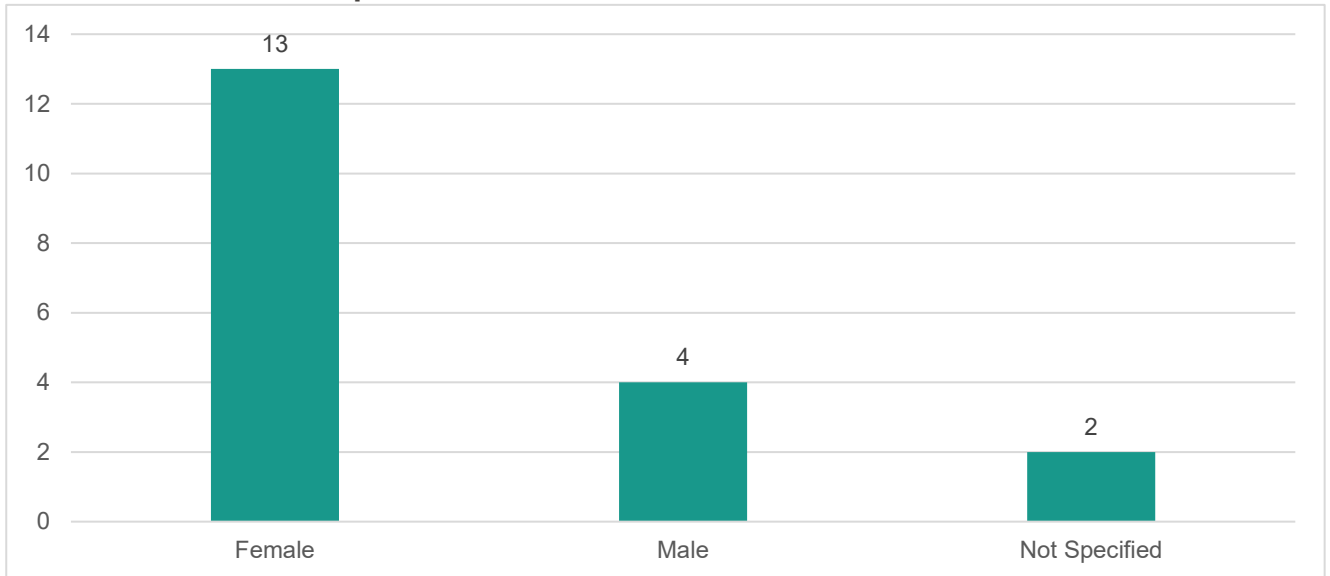


Table 2. Age of Respondents

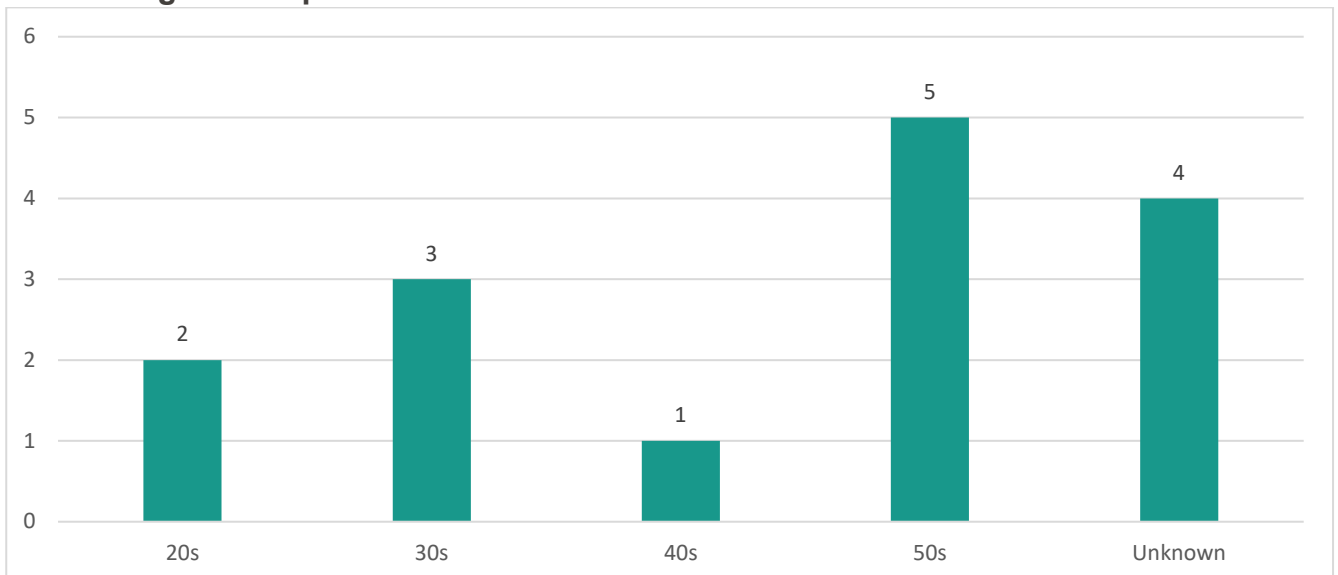
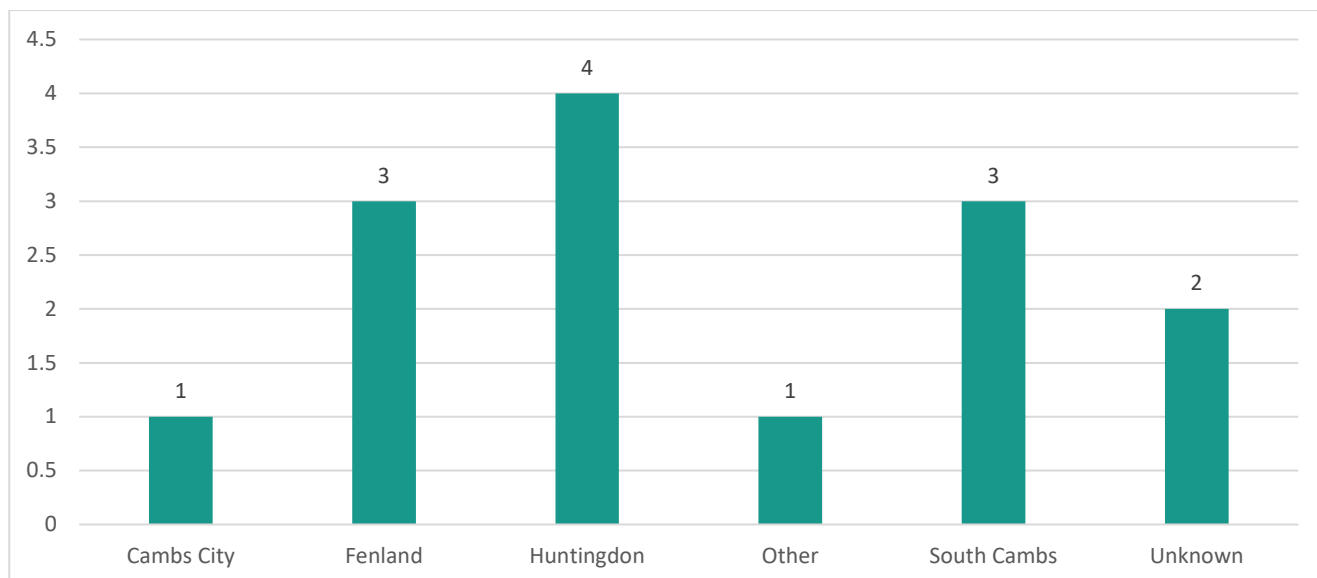


Table 3. Location of Respondents



Qualitative Feedback

Opinions on Available Information

Key Themes:

- No concise trustworthy information available
- Misinformation via social media
- Word of mouth

Qualitative Data:

'There is not good information available about ADHD, I have spent up until now thinking it was more about hyperactivity. Society tells us it's people who are in prison or commit crime, very negative connotation. My social media actually alerted me to signs and symptoms and that is where I have got a lot of information. The NHS website is too basic and too general. Doesn't really relate to the female signs. I also have read some articles and there are tonnes of tests you can do online - would be good if there were some fact-checked, scientific and safe documents and information out there. There is no clarity about the difference of male and female presentation. I also feel embarrassed that if I don't get a positive diagnosis, where does it leave me? I still need support with something. I have a degree and have studied and could hold down a job, so have I really got it or am I making it up? Misinformation about neurodiversity and mental health disorders too - so unclear on what it is and how it actually affects people'

'I was alerted by my colleagues that I may have ADHD (they work within the health and social care system) so I did some of my own research and went to the GP, I read the Gabor Mate book about it which states that ADHD is from trauma'

'People need to understand what it actually is'

'There needs to be better information and education for all'

Focus Group Feedback (5 people): 'Such bad information available, we looked at YouTube and social media. We can't work out how the system works. There's a lack of knowledge at GP level and it's not taken seriously, as soon as you mention ADHD you get dropped. There

is no local information. Everyone seems dismissive with a lack of understanding. There are no resources. We are the ones who research and educate people. ‘

‘There is none, there is a great site called ADDitude which I use that has lots of information. NHS and NICE guidelines are totally out of date’

‘I have found the information available very limited, particularly in relation to helping other people understand’

‘Online’

Understanding the Diagnosis Process

Key Themes:

- Right to choose (RTC) is very confusing
- Waitlists are too long
- Process seems vague

Qualitative Data:

‘Right to choose is so confusing, it would be good if there was someone to be able to help you go through that process as it’s so overwhelming. I have had texts about the fact that I am on the pathway but that’s it. People who suspect they have ADHD procrastinate and get overwhelmed with mass info and that is what the right to choose info is - TOO much’

‘I knew it would be a long waitlist so went on the RTC pathway, which is really hard to navigate for someone like me and I had to ask my colleagues to help me, but I know it means I’ll get an appointment more quickly’

‘I was diagnosed with autism in 2019, put on waitlist for ADHD in April 2021 and was diagnosed in July 24 via RTC. Now I have to wait 8-10 months for medication’

‘Very unclear, RTC is very confusing, and all the appointments are not face to face. Also, the not always recognised by the GP if there is no shared care agreement’

‘I do not have a diagnosis yet, I have completed the referral form and had one telephone call appointment to complete some additional information and am now on the waiting list, but I haven’t been told much about the process other than it’s a long wait’

‘Very lengthy and hard to diagnose in women’

The Meaning of a Diagnosis

Key Themes:

- Understanding of self
- Understanding of behaviours
- Potentially unlocks support

Qualitative Data:

‘Diagnosis would give me and understanding of myself and also be able to tell people around me why I am the way I am. A label. It’s bad that for a lot of conditions, you have to have a diagnosis to access help’

‘I want to understand why I can’t do things that everyone else seems to be able to do, it almost do it gives me a reason’

‘No diagnosis means no support from society’

Focus Group Feedback (5 people): ‘Helped me understand and made me realise that I couldn't do all these things that others could for a reason. Allowed me self-compassion and to be kinder to myself, showed me my strengths. Practitioners don't see the power of a diagnosis. If you don't know what it is, how can you fix it? I want to help my kids and help the next generation. Diagnosis means you are protected under the Equality Act. Made sense of my history and I did feel optimistic for a while (I thought the drugs would work) but very little has changed’

‘I think with such long lists now support is necessary even without diagnosis’

‘Gives access to medication when the other things that could be available are not always going to work if that person isn't well enough. It gives us so much in terms of understanding. It doesn't feel like there is an understanding of the complexity of the condition from the medical practitioners. People can't always access (skills) support if they aren't well enough’

‘Currently I don't 100% know where all my difficulties are coming from, I feel like I will be able to better understand myself and be kinder to myself if I know why and can work to find ways to manage better. I also feel lost as there is no support or help available without a diagnosis, I have been told that even the mental health team are not able to support me in any way due to the belief that I have ADHD and I will have to wait to access the adult ADHD clinic for support’

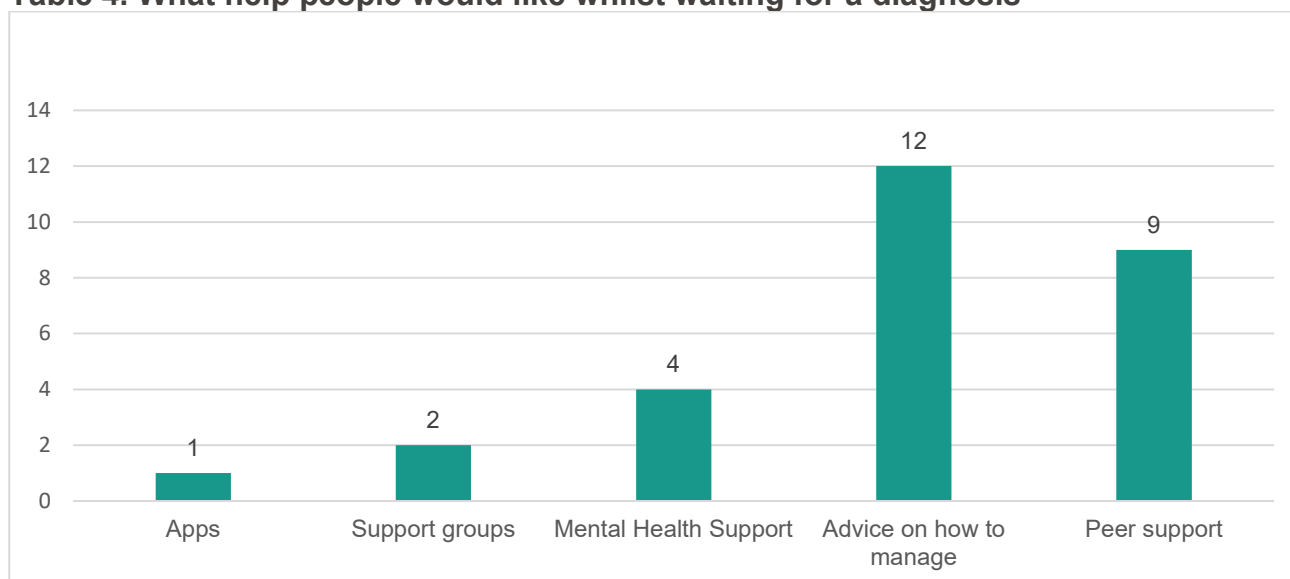
‘Understanding of who I am and able to seek right support’

Help Whilst on the Waiting List

Key Themes:

- Peer support and coping skills
- Apps can be hit and miss

Table 4. What help people would like whilst waiting for a diagnosis



Qualitative Data:

‘Understanding what ADHD is’

'Skills based help and peer support would be the most helpful'

'Skills based help would be really helpful, so I can manage my day to day'

'Education and skills help, this will help people to know if they actually need to be on the waitlist or not'

Focus Group ideas/comments:

'Ongoing psychological skills or organisational help'

'Centralised NHS resources'

'Non-medical language'

'Examples of ADHD'

'GP education'

'A structured course'

'App – would get very bored of and wouldn't want to pay. Also it's a bit faceless'

'Needs led help'

'Peer support groups would be absolutely invaluable. We learn so much from each other! At the moment with the lack of support from doctors, being able to share experiences would be invaluable. Waiting well support'

'I didn't know what ADHD was properly until my diagnosis'

Help During the Diagnosis Process

Qualitative Data:

'Help with right to choose pathway'

'I feel like there is no support while waiting, given the waiting list is years long, some contact would be nice. Even just some access to support groups or mental health support so that there is a space to 'vent''

'Reading materials'

Using Digital Support (Apps)

Qualitative Data:

'Yes I would use them'

'Yes absolutely, it would be particularly great to have something to support those on the painfully long waiting list'

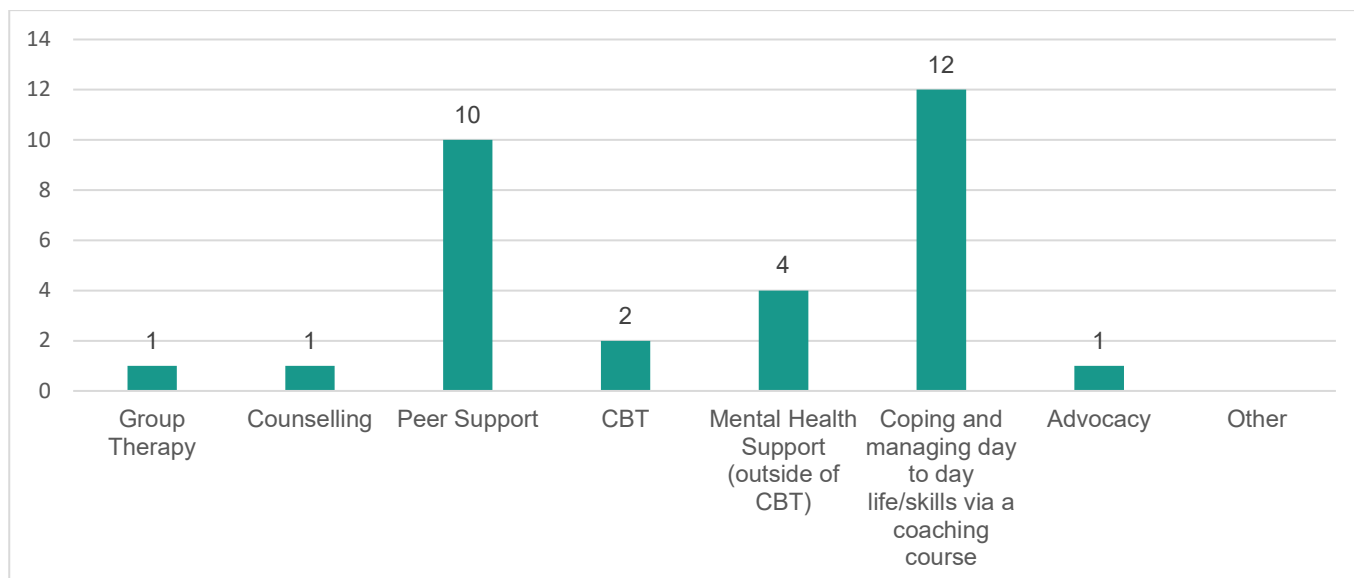
'Yes'

Post Diagnostic Support

Key Themes:

- Skills via a coaching course
- Peer support
- Person centred approach

Table 5. Showing which type of support participants would like after a diagnosis



Qualitative Data:

'I had adaptive CBT for autism and that really helped as they spoke to me like a neurodiverse person.

Therapy could help? To be able to be 100% yourself, not have to mask, and to offload and receive therapy (CBT, DBT - whatever it is) alongside talking. Person centred care catered for that person. These people are dealing with it all themselves and its tiring living in a world where people don't believe you and a world that isn't set up for you'

- Focus Group ideas:
 - Workplace acknowledgement
 - Non-medical language
 - Examples of ADHD
 - GP education
 - A structured course
 - Not just meds
 - App – would get very bored of and wouldn't want to pay. Also, it's a bit faceless
 - Need led help
 - Wider services acknowledgement (neurodiversity informed care)
 - Peer support groups would be absolutely invaluable. We learn so much from each other! At the moment with the lack of support from doctors, being able to share experiences would be invaluable.

'I think CBT has its benefits for ADHD and there is a place for it definitely and would be good to be offered but needs not to be the only therapeutic intervention on offer. Not a blanket approach. The practitioner would need to be immersed in ADHD awareness and neurodivergent affirmative practice. Useful for self-negativity shifting and self-perception'

'Mental health support would be good for the ADHD, not the comorbid conditions. Apps may be useful but ADHDers get bored of that sort of thing. It may be worth having pre and post offers of therapy. Some people feel with more tools that they can manage and don't want medication. For some, medication is not an option due to health conditions and medicine side-effects, certain heart conditions etc'

Most Important Skills Support

Qualitative Data:

'Day to day organisation' (this is essentially what everyone said)

'My biggest problems are starting tasks, concentration and focus, which heavily effects my ability to do my work'

Diagnosis, if Support was Available

Key Themes:

- Very subjective and hard to say

Qualitative Data:

'Yes, it will still help me to understand myself'

'If that type of skills based help was available, I might not need a diagnosis, no'

'I would still absolutely access a diagnosis – for all the reasons mentioned'

'I don't know. I think that it would depend on the outcome of that support, if I found that I was better able to manage work and home life then potentially I would not feel the need for an official diagnosis'

Focus Group: 'Mixed, it's hard to say what that would look like as that support could help alleviate problems BUT diagnosis can give so much in terms of identity, self-compassion and understanding'

'Yes'

Additional Comments about ADHD Experiences

Key Themes:

- People feel lost
- Healthcare and VCSE support are not neurodiversity informed

Qualitative Data

'When I had a call with primary care, she was really helpful but couldn't signpost me to anything when she told me the waitlist was 5 years. I felt shocked and disheartened. I was signposted to REDS'

'My only comment would be that everyone from my GP to the mental health team have been great, it is just a shame that once ADHD is mentioned you are left floating around with no support'

'I feel like I've slipped through the net and been given other medication for stuff that I have but don't give the full extent of my symptoms'

'I have done loads of online tests and it says I have it, but the GP wants to sort out my mental health first and then think about ADHD. Do you think I have it?'

'I think I have ADHD and/or Autism but I am too scared/overwhelmed to proceed with diagnosis. In my work I see a lot of people with a neurodiversity, and I see how long it takes

for people to get a diagnosis, and how confusing and stressful the process can be. So it puts me off

'I would like to take an interest in the ADHD one I think I may have it, I'm waiting diagnoses for autism ASD final assessment. Bit don't know how to access the ADHD process'

'I have done some pre-test things with Cambridgeshire and Peterborough Foundation Trust (CPFT) for Autism, and they have put me on the waiting list. I don't know what I sit with a diagnosis or anything. I know there is something more than my Emotionally Unstable Personality Disorder (EUPD) and addiction, EUPD doesn't feel like that's the only thing and an Autism and ADHD diagnosis will hopefully make me feel like I can understand myself more. I had LSD induced psychosis and have had psychosis ever since. CGL are very good at supporting me with my addiction issues, but I don't get support with my mental health. There is also no neurodiversity (ND) support from them either. I need an ND diagnosis to feel seen and understood. I did an online ADHD assessment and scored highly. I need the right medication for all my diagnoses so I can feel right. Because there is no support, people are self-diagnosing and don't understand that it is actually a daily struggle, and I can't fit in. The wrong medication leads to people self-medication with drugs and/or alcohol to feel better. I have used REDS service. I used to have a community psychiatric nurse but because I couldn't drive to the appointment, they discharged me from the personality disorder service and that was it. No more support. Group therapy is good for a social aspect, but it isn't for everyone, and I need 1-2-1 support. I've had loads of treatment, but it's all stopped. Thankyou for the opportunity and listening'

'There is stigma about autism, I got told by people I don't have it because I'm too chatty. CPFT told me I am too complex and referred me to my GP. I also have ADHD. I took cocaine as it felt like ADHD medication and that worked for a while, but I realised that it was becoming unhealthy. Now I smoke weed (cannabis) every day to help with the sensory processing, CGL have discharged me because there isn't anyone who can help. Services are not neurodiversity informed at all. I have been misdiagnosed with EUPD as the ASD and ADHD are fighting against each other and it shows traits of EUPD, a diagnosis which is now 'inactive' on my medical notes. A lot of people get misdiagnosed. Professionals, parents, organisations, society all need to have neurodiversity training, people just don't get it and we get accused of lying as we don't fit a mould that people think ADHD or ASD is. This applies to medical and VCSE professionals massively'

'Once you have a diagnosis nothing happens'

'I felt like a ping pong ball from one service to another until I was sent to RCE.... (I am on waitlist)'

'There is no information available, particularly after diagnosis, no info on waitlist time, there is no one there in an emergency. There is a lack of information about medicine interaction we need a neurodivergence service, not an ADHD and then ASD service as there is a massive ADHD/ASD crossover'

'I don't want it to be viewed as an "easy fix" as the underlying brain structure is not changeable. It is not all about tools or self-management but they are helpful to some extent. It's again about a holistic person-centred approach, which we deserve and would make a massive difference to the economy, school, university, wider health and injury issues. It all depends on their executive functions and the impact of ADHD

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11221408/> new research on CBT and ADHD - Overall, participants found non-adapted, generic CBT in the UK to be unhelpful, overwhelming, and at times harmful to their mental well-being. Therefore, it is necessary for clinical bodies in the UK, while following the indicated NICE guidelines, to be mindful of adapting CBT delivery of CBT, to be most effective for people with ADHD and to mitigate potential harm. I'd like the ICB to see this please'

Conclusion

Thank you to everyone who took the time to speak with The SUN Network or to fill in an online survey. It has been really interesting to hear the challenges and thoughts of people who are either going through the process of an ADHD diagnosis or have had a diagnosis.

There are some interesting pieces of feedback that have been brought up thematically throughout conversations and the strongest, most important themes have been identified. However, there are some themes that spanned several questions, and it is important to note that GP Education, Patient Education, and Neurodiversity Informed Care are three items that are repeated throughout this report but in separate sections. So these three are highlighted as additional themes

Overall, participants felt that there was a lack on centralised, reliable information via any professional bodies, and the majority of information was found via social media channels. Diagnosis is certainly important to people and it evoked some very emotional responses, but there is certainly a question pertaining to whether this actually unlocks and help and support for people generally. When participants were asked if they'd still want a diagnosis if they had access to needs led support, some were unsure. This is also a particularly hard question to answer as participants couldn't envisage what that would look like. Based on the findings in this research, that would certainly be something to consider reviewing when any ADHD service is designed: 'are you satisfied with the needs led help you have, or would you like a diagnosis?'. And asking the question about what a diagnosis means, again.

Overwhelmingly, there was a strong sense from the participants that peer support and a structured coaching course covering day to day managing would be the most helpful thing, pre and post diagnosis – when compared with the other support options. Also, referring back to the opening of this conclusion, it is important to think about how the wider system (NHS and VSCE) can be better informed about ADHD as a condition, and how services generally can improve their access and processes for neurodiverse individuals.

Recommendations

Based on this feedback, there are some clear recommendations that are suggested:

- 1) Co-produce information for people seeking reliable information about ADHD. To include real life/lived experience testimonials and examples
- 2) Co-produce a needs-led service that can help people needing support with organisational skills and day to day management tasks
- 3) Co-produce a post diagnostic support service that provides people with an ADHD diagnosis personalised support
- 4) Educate and inform the system about ADHD, ADHD interplay with other conditions and ADHD informed care and acknowledge the complexities of living with ADHD

Questionable to the above is what does a pre and post diagnostic support service look like, when people are looking for the same type of support before and after a diagnosis. There is an idea here to create a general needs-led service, with the option of diagnosis for those that may need medication or are experiencing more complex symptoms with comorbidity of other conditions. It must be said, the 20 people in this report are not representative of all of the different experiences of ADHD and there will be people within the general population that require something more than a coaching course and peer support, based on their individual situation. This is where a person-centred model would be effective within the support suggested. Having said that, there is a strong desire from the ICB to co-produce a potential ADHD service with people with lived experience of ADHD, therefore these sorts of questions would indeed be debated within those groups.

Appendix

ADHD Survey

1. Which area do you live?

*Cambridge City
East Cambridgeshire
South Cambridgeshire
Huntingdonshire
Peterborough
Fenland
Other*

2. Please tell us your age:

3. Please tell us your gender:

4. How would you describe your ethnic background?

5. What is your opinion on the information about ADHD that is currently available?

For example: Do you know where to look for support? Were you able to find accurate, reliable and trustworthy information to better your understanding of the condition?

6. What is your understanding of the ADHD diagnosis process?

7. What does a diagnosis mean to you/give you?

8. What could help you whilst you are on a waitlist?

*Apps
Support groups
Mental Health Support
Advice on how to manage
Peer support
Other*

9. What would help you during the diagnosis process?

10. Would digital support, like apps – be useful for you?

11. What support would be helpful after a diagnosis?

*Group Therapy
Counselling
Peer Support
CBT
Mental Health Support (outside of CBT)
Coping and managing day to day life/skills via a coaching course
Advocacy*

Other

12. Which skills do you need help with the most?

13. If you could access help and skills support without a diagnosis, would you still look to get a diagnosis? Could you explain your answer in more detail.

14. Is there anything else you would like to tell us about your experiences with ADHD?