

**Review of the
Attention Deficit Hyperactivity Disorder Service
for Children & Young People to age 18 in Fife**

**Participation & Engagement
Feedback Report**

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Introduction

In 2023-2024, the Fife Health & Social Care Partnership (HSCP) began undertaking a review of the Attention Deficit Hyperactivity (ADHD) Service for Children & Young People (CYP) to age 18 in Fife.

Current ADHD (CYP) provision is a 'matched care' model comprising three pathways: Tier 2; Tier 3; and CAMHS (the Children & Adolescent Mental Health Service). Tier 1 comprises universal/community care provision and is outwith the scope of the review. Although each part of the pathway is managed discretely, there is collaboration between them as well as multi-agency liaison.

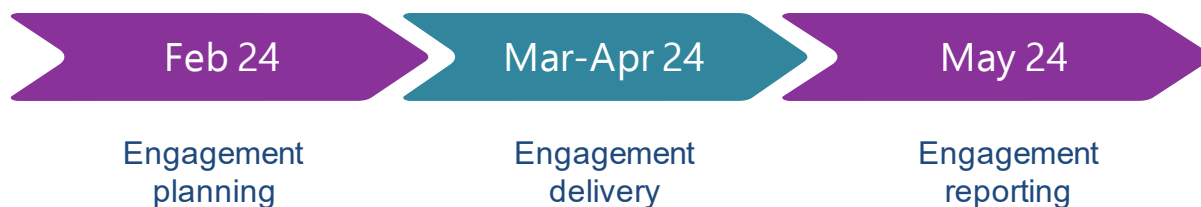
The purpose of engagement was to gain an understanding of the views and experiences of those who use, plan and deliver ADHD (CYP) services to inform recommendations for future provision.

This report provides a summary of the feedback which was received during a 3-week engagement period.

Engagement timeline

Stakeholder engagement took place over a 3-week period during April – May 2024. The engagement timeline is shown in Figure 1:

Figure 1: Engagement timeline



Engagement aim

The aim of engagement was to capture the views and experiences of those who use, plan and deliver services and supports across the three ADHD (CYP) pathways in order to understand what is important to people in relation to accessing, receiving, and leaving ADHD (CYP) services; the extent to which services and supports match what is important; and what changes can help improve experience.

Engagement methods

Engagement took the form of a survey (Appendix 1) which was made available to members of the public and to delivery partners (Appendix 2) both online and in paper form. An 'easy read' version of the survey was also available but was not requested. A link to the survey was promoted in the following ways:



- Fife HSCP and NHS Fife websites
- Fife HSCP and NHS Fife social media sites
- Directly to service users at an ADHD (CYP) event
- Directly to service users at ADHD (CYP) clinics
- Directly to delivery partners both internally and externally

Survey questions were designed to capture:

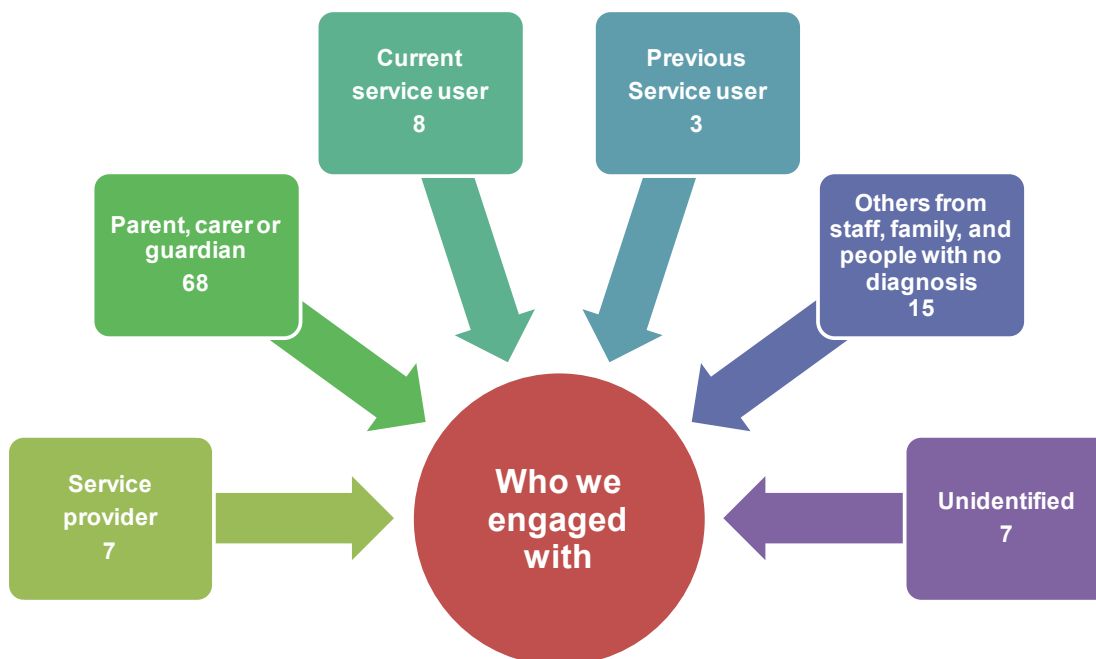
- What is working well with ADHD (CYP) services?
- What is working less well with ADHD (CYP) services?
- What is important at each stage of the ADHD (CYP) journey?
- To what extent services and supports match what is important? and
- What changes could improve experiences of ADHD (CYP) services?

Engagement reach

Survey respondents

The consultation received **108 responses** from stakeholder groups. A breakdown of survey respondents is given in Figure 2.

Figure 2: Survey respondents

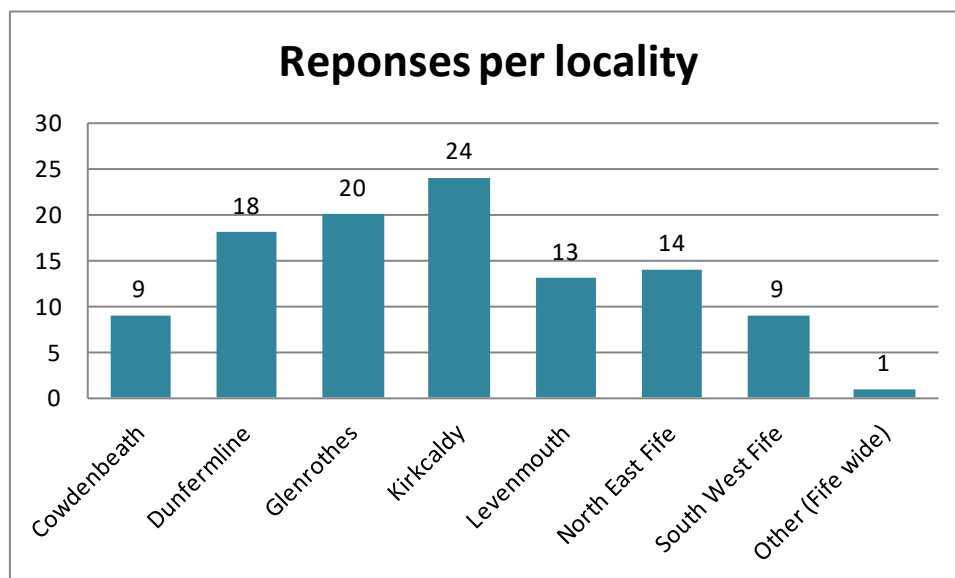




Localities

Responses to the survey were received from all 7 localities across Fife. The number of responses per locality are given in Figure 3:

Figure 3: Responses per locality



Equality, diversity and inclusion

Of the 108 survey responses received, 61 people (56%) completed the equality, diversity and inclusion questions. The data is given in Appendix 3.

Engagement feedback

Key themes from feedback relating to the survey questions are summarised in the paragraphs which follow. Further analysis of feedback is given in Appendix 4.

What is working well with ADHD (CYP) services?

Of the 108 survey responses received, 93 (86%) responded to this question. 62 respondents (67%) highlighted positive experiences and 31 (33%) highlighted negative experiences of ADHD (CYP) services. Themes from positive and negative feedback are given in Figures 4-5.



Figure 4: Positive experiences of ADHD (CYP) services



The responses reflected positive experiences relating to staff, appointments, prescriptions, having a point of contact, the PINC course and ‘everything’. Responses under ‘Other’ reflected comments from people who said that it was too early to say specifically. Examples of comments from respondents on their positive experiences of ADHD (CYP) services are given below:

“Staff are helpful when you see them and definitely try to do their best”

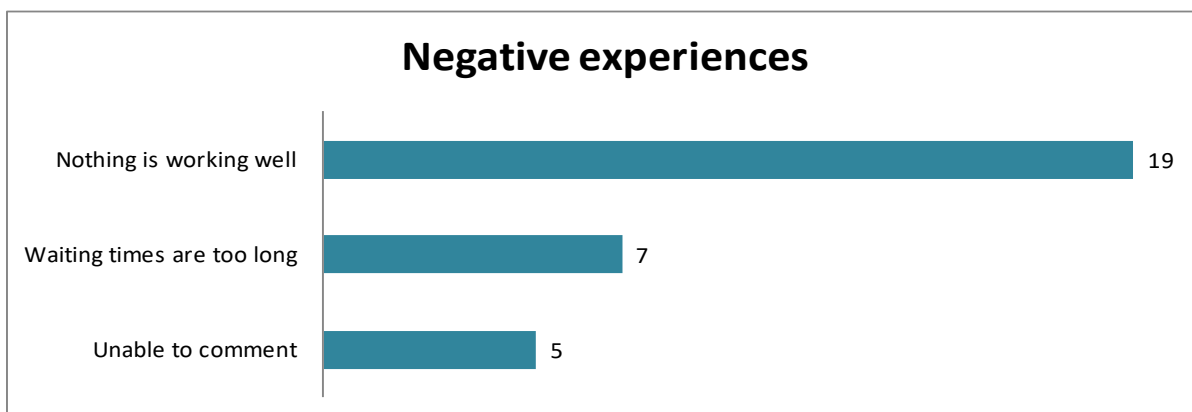
“The professionals we’ve been involved with have been great, very supportive, helpful, genuinely working to provide more information and help for parents and children with ADHD”

“Email ADHD medication ordering system”

“PINC was best intervention I have had”

“We have only just started accessing the services so too early to say”

Figure 5: Negative experiences of ADHD (CYP) services





The responses which reflected negative experiences related to waiting times or of the service generally. Examples of comments from respondents relating to their negative experiences of ADHD (CYP) services are given below:

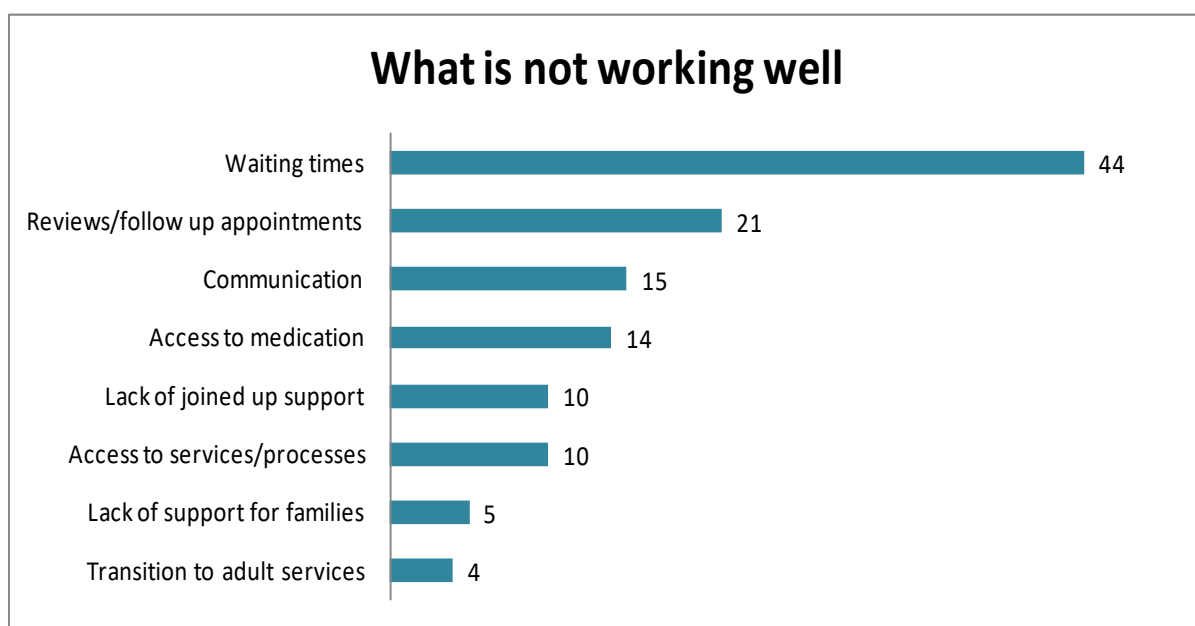
“Not very much, waiting times are crazy”

“Nothing [is working well]. My child hasn't been seen by ADHD Dr since first lock down and that was via video”

What is not working well with ADHD (CYP) services?

Of the 108 survey responses received, 103 (95%) responded to this question, identifying 123 elements which were not working well with ADHD (CYP) services. Themes are given in Figure 6.

Figure 6: What is not working well with ADHD (CYP) services



The responses reflected negative experiences relating to waiting times, review appointments, communication, medication, joined up care, access, support for families, and transitions into adult services. Examples of comments from respondents on what is not working well are given below:

“Diagnosis took a year, then [there were] medication changes from stimulant to non stimulant due to not coping with the anxious feelings [that the] meds caused. Guardians [were] left to try [and] manage a situation with no support. Continual change of psychiatrists, so lacked momentum in moving forward. Constantly fighting for help and support is just exhausting”

“The referral process, the diagnosis process, the support systems, the medication, the access and wait times to all of these things. [The staff] that



assessed and misdiagnosed me [were] incredibly unprofessional, unsupportive and didn't seem to factor in any of my lived experiences, my experience as an undiagnosed woman/child/teen, or the fact I fill the criteria and instead misdiagnosed me and left me with zero hope for the future and zero trust in myself or the system"

"The assessment process for a diagnosis is too long and there isn't enough staffing to improve this yet. The children are often older and have trauma from trying to fit in with no diagnosis"

"Often there is a lack of information as to where you are in the process. Greatest concern at the moment is the transition to adult services where there is no service"

What is important to people at each stage of their journey?

To elicit what was important to people at each stage of the ADHD journey, the survey asked 5 questions:

What is important **prior to being referred** to ADHD (CYP) services?

What is important **when being referred** to ADHD (CYP) services?

What is important **when waiting for** ADHD (CYP) services?

What is important **when receiving** ADHD (CYP) services? and

What is important **when leaving** ADHD (CYP) services?

Each of the questions contained options which respondents could select and the opportunity to add any additional points that they considered important. The option for each of the five questions which was selected most often, relating to what is important at each stage of the ADHD journey, is highlighted in Figure 7.

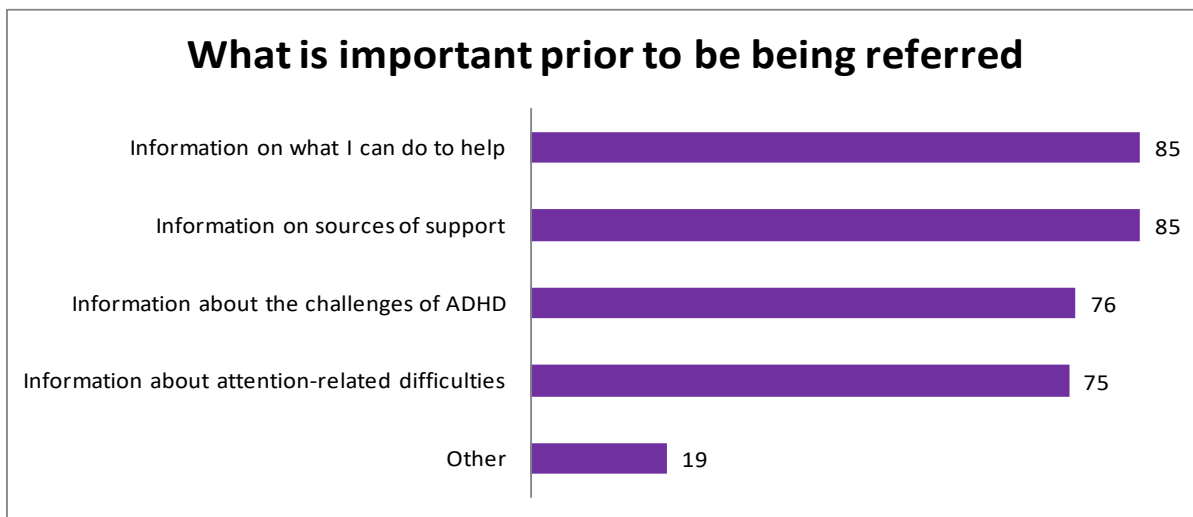
Figure 7: What is most important at each stage of the ADHD journey





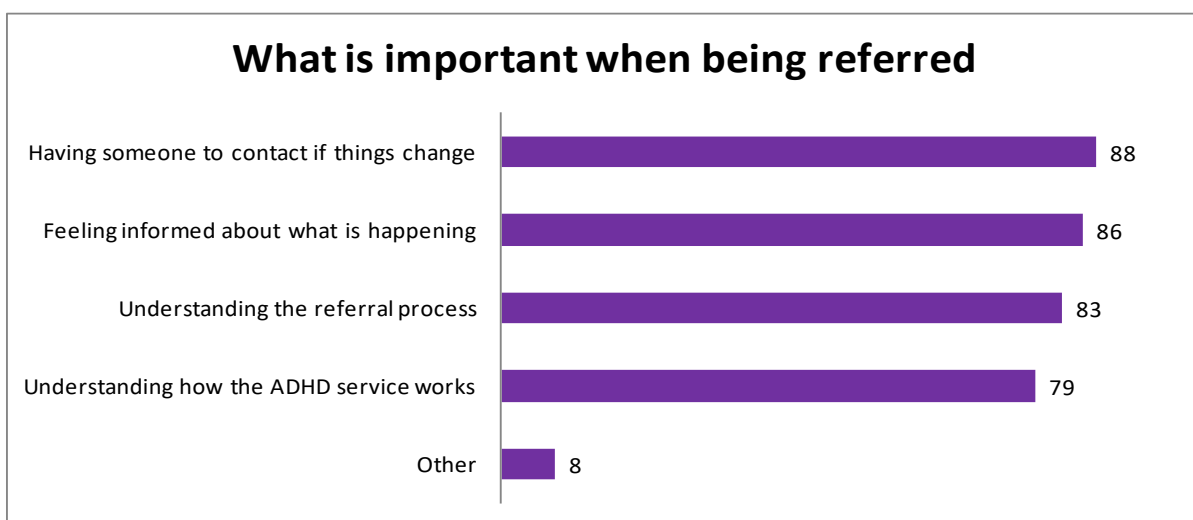
A summary of the key themes relating to each of the five questions is given in Figures 8-12. Note that respondents may have selected more than one option within each question.

Figure 8: What is important prior to being referred



Themes included having information on the challenges and difficulties associated with ADHD and the self-care and supports that are available. Responses under 'Other' related to having information about waiting times and recognition and awareness of the impact that a lack of diagnosis can have.

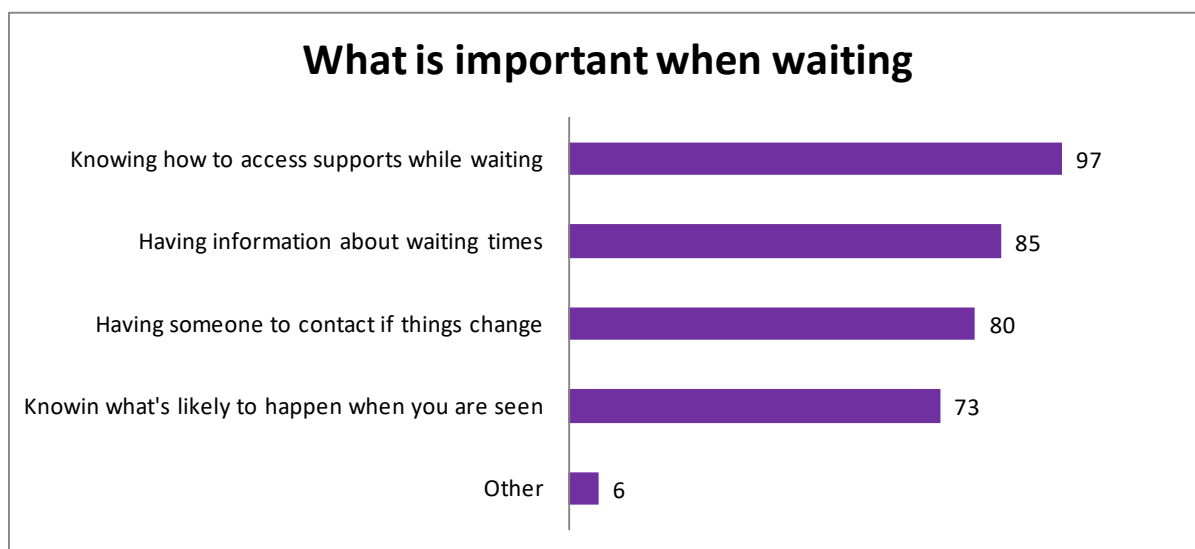
Figure 9: What is important when being referred



Themes included having a point of contact, feeling informed and understanding service processes. Responses under 'Other' included having access to support and information, being seen and being believed, and an awareness that every child matters and not just those who are 'desperate'.

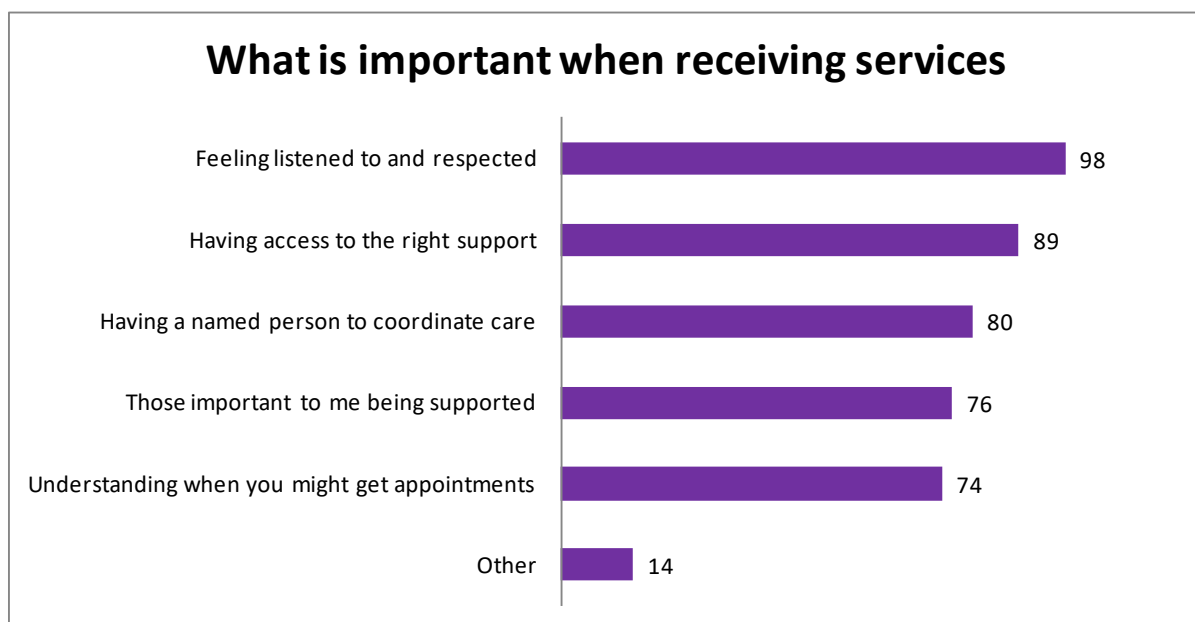


Figure 10: What is important when waiting?



Themes included knowing how to access supports, having information about waiting times, having someone to contact and knowing what is likely to happen once seen. Responses under 'Other' included having access to information, and signposting to services and groups which can offer support.

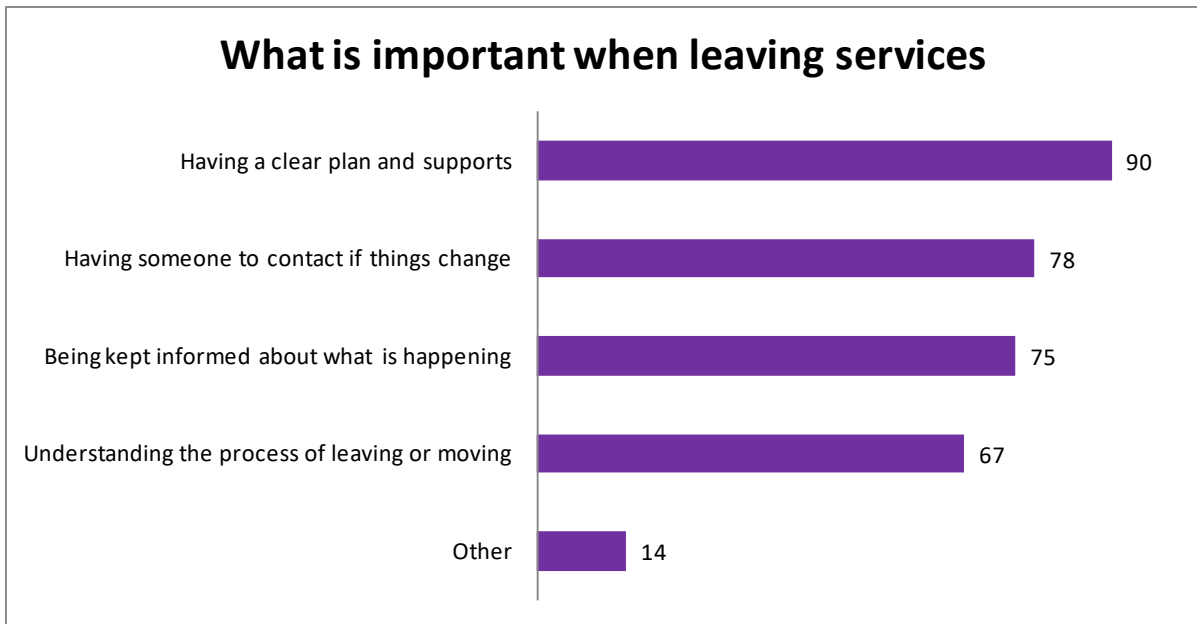
Figure 11: What is important when receiving services



Themes included feeling listened to, accessing the right support, having a named coordinator, support for family, carer or guardian, and understanding appointment processes. Reponses under 'Other' included having contact details of a named practitioner, support for families, and keeping people updated.



Figure 12: What is important when leaving services

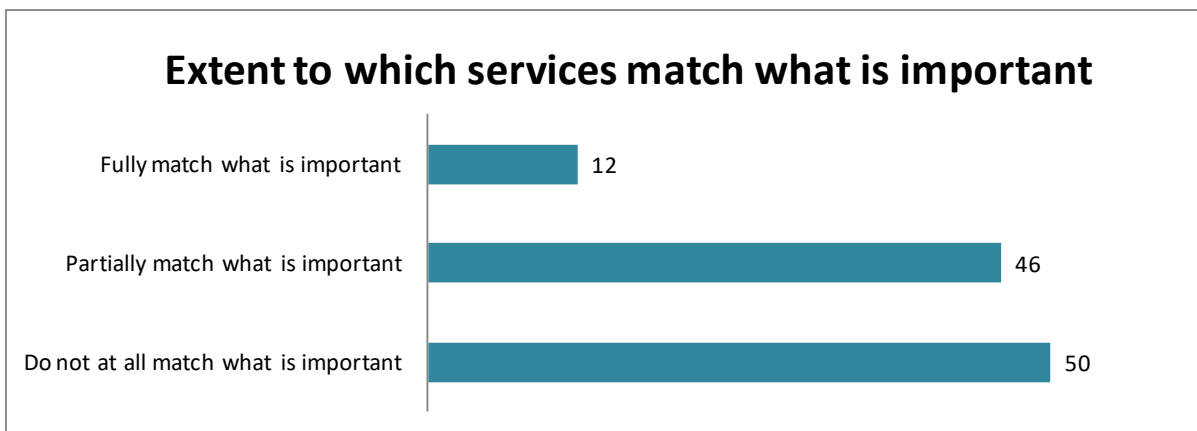


Themes included having a clear plan and supports, having someone to contact, knowing what is happening, and understanding the process of leaving. Responses under 'Other' included having continued support from other services, and smooth transitions to and support from adult services.

To what extent do services and supports match what is important?

Respondents were asked to select whether ADHD (CYP) services matched what is important fully, partially or not at all. A total of 108 responses were received and are given in Figure 13.

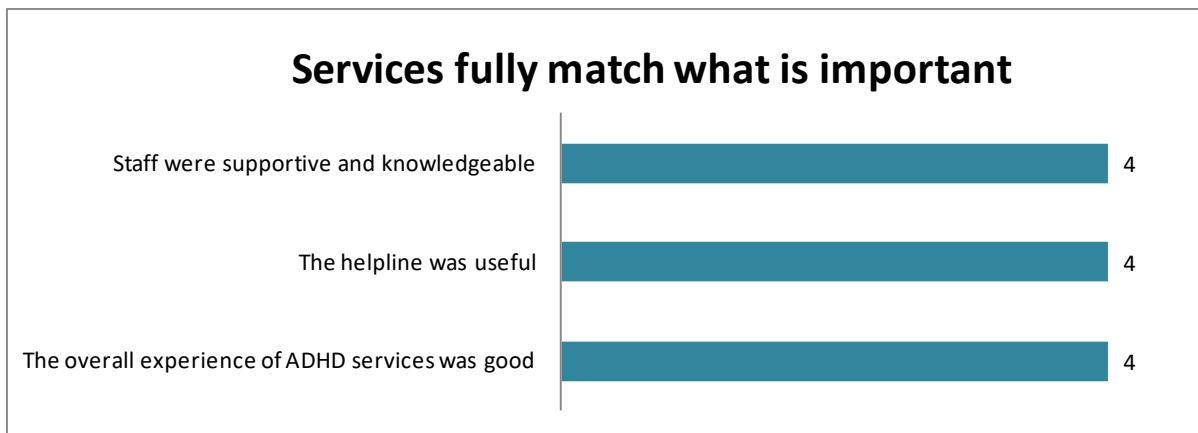
Figure 13: Extent to which services match what is important



Respondents were invited to say more about why they responded this way. Themes are given in Figure 14-16 below.



Figure 14: Services fully match what is important

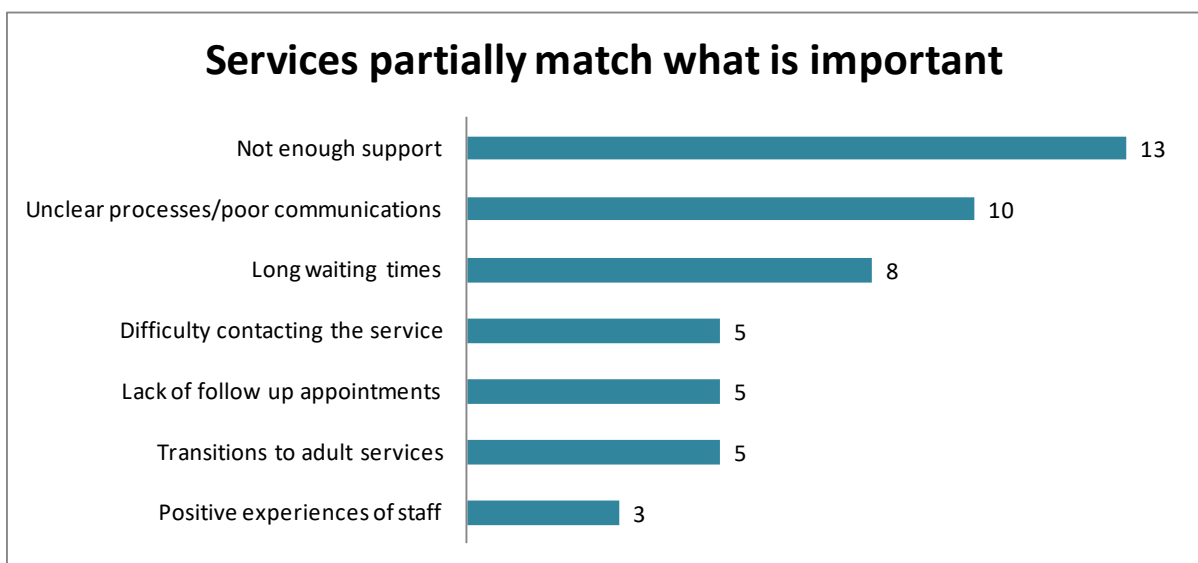


Themes included supportive and knowledgeable staff, having a helpline, and the overall experience of ADHD services being good. Examples of comments from respondents on how services fully match what is important are given below:

“Great experience with ADHD Service, children are on different pathways and both working well”

“The professionals we’ve been involved with have been great, very supportive, helpful, genuinely working to provide more information and help for parents and children with ADHD. My son is supported well and we always know who to contact”

Figure 15: Services partially match what is important



Themes related to levels of support, communications, waiting times, contacting the service, follow up appointments and transitions to adult services. Positive themes



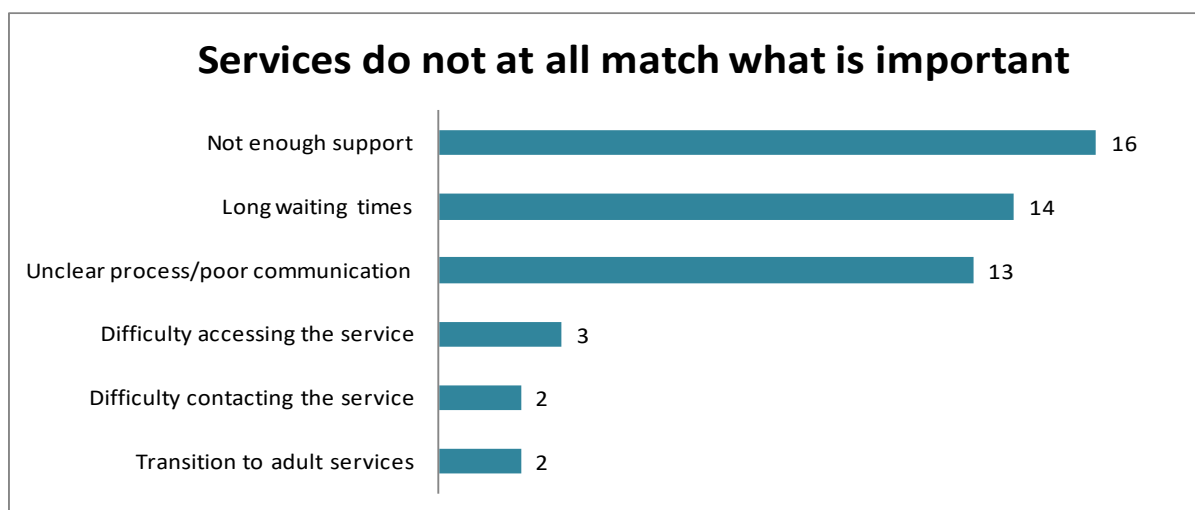
related to experiences of staff. Examples of comments from respondents on how services partially match what is important are given below:

“It’s not clear from referral to assessment how the process should work. When you are waiting and the child’s symptoms are worsening it is not clear where to go for advice / support on how to help them. Even once assessment is given there was no direct named place/person to go to for further support. Maybe a flow chart or information on next steps could be included”

“More information around support services aligned to ADHD would be worth sharing”

“More info about the process, what happens at appointments, who to contact and other support services”

Figure 16: Services do not at all match what is important



Themes related to levels of support, waiting times, processes and communications, ease of access and contact, and transitions to adult services. Examples of comments from respondents on how services do not at all match what is important are given below:

“Very little communication between services, parents have to repeat their stories and becomes more difficult if receiving some support outwith Fife e.g. if live on the border - there should be better communication between all”

“From school referrals [the] process is long, no clear communication what happens during referral and waiting to be seen”

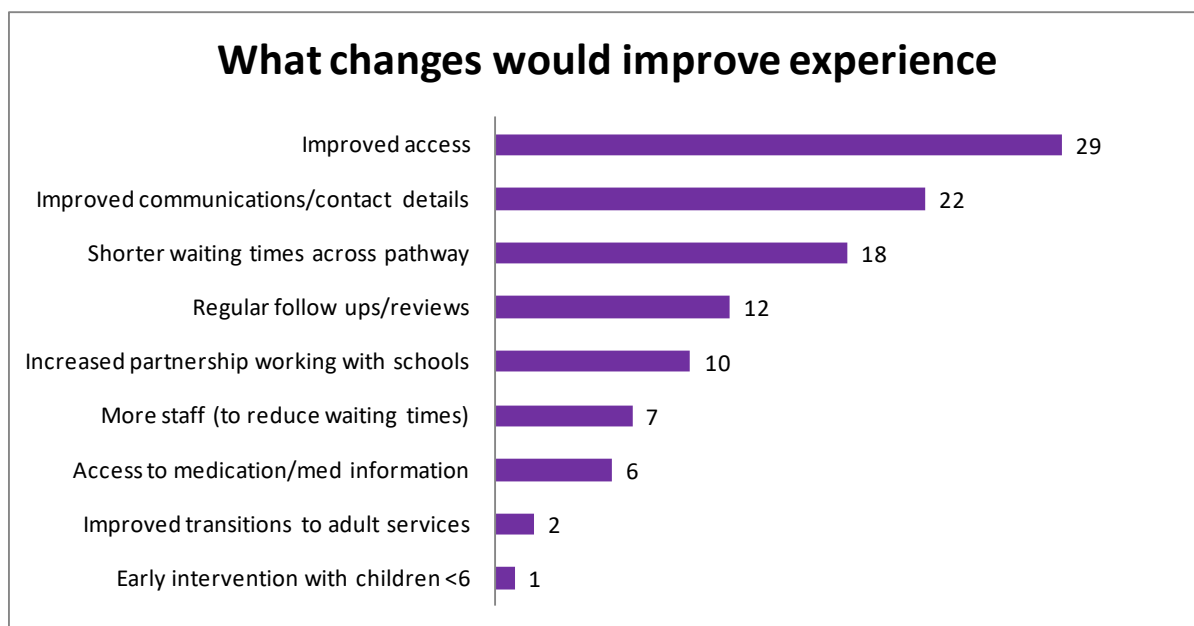
“While waiting for assessment no support was available”



What changes would improve experience of ADHD (CYP) services?

Respondents were asked to identify changes which would improve experience of ADHD (CYP) services. A total of 100 responses were received and key themes are summarised in Figure 17.

Figure 17: Changes that would improve experience of services



Themes related to access, communications, waiting times, reviews, partnership working, staffing, medication, transitions and early intervention. Examples of comments from respondents on what changes could improve experience are given below:

“Having allied health professionals and non statutory agencies running alongside the team. Services are there but not joined up thinking and sharing of resource”

“More joined up thinking, clearer and consistent information with the services involved in the child's life, other services being able to access information on how to work with children with ADHD and how to identify possible ADHD”

“Better communication and shorter time frames with the addition of resources to help families whilst waiting for a service”

“A central email point to send information and queries to”

“Better communication and shorter time frames with the addition of resources to help families whilst waiting for a service”



Conclusion

The purpose of engagement was to gain an understanding of the views and experiences of those who use, plan and deliver ADHD (CYP) services to inform recommendations for future provision as part of a Fife HSCP review.

The aim of engagement was to capture the views and experiences of those who use, plan and deliver services and supports across the three ADHD pathways in order to understand what is important to people in relation to accessing, receiving, and leaving ADHD (CYP) services; the extent to which services and supports match what is important; and the changes which would help improve experience.

Engagement took the form of a survey which was made available to members of public and to delivery partners both online and in paper form. It was promoted to members of the public on Fife HSCP and NHS Fife websites and social media and was sent directly to a range of stakeholders. A total of 108 responses were received.

Survey feedback identified a number of themes including a range of challenges and opportunities for improvement. These pointed to early opportunities for improving elements of the patient journey, alongside longer-term changes which would require a more systemic response. Changes that could improve experience related to access, communications, waiting times, reviews, partnership working, staffing, medication, transitions and early intervention.

The feedback provides an opportunity for the review to consider what patterns of provision can meet contemporary needs and expectations, and to inform recommendations for future service design and delivery of ADHD (CYP) services in Fife.

Next steps

1. This report will be presented to the Fife HSCP ADHD (CYP) Review Group and thereafter will be published on the Fife HSCP website for members of the public to view and shared with respondents who indicated that they would like to receive a copy when completed.
2. The next stage of the review will be to develop options for the future provision of ADHD (CYP) services in Fife. The feedback will be used to inform design and delivery of provision.
3. The outcome of the review will be submitted to the Fife HSCP Integration Joint Board for consideration.

NHS Fife and Fife Health and Social Care Partnership would like to thank everyone who responded to this consultation for their time and for sharing their views.



Appendix 1 – Survey



Review of ADHD Services for Children and Young People

The Fife Health and Social Care Partnership and NHS Fife are undertaking a review of the ADHD Service for children and young people in Fife. We are carrying out this survey to understand the views and experiences of people who use and/or provide ADHD services to inform recommendations for developing the service.

This survey should take approximately 15 minutes to complete.

The information that you provide will be anonymous and will be included in reports and presentations – you will not be identified. Further information on data protection and how we use the information you provide is available on our website: www.fife.gov.uk/kb/docs/articles/privacy-notice/health-and-social-care

If you require assistance, or would like this form in an alternative format, please contact:

Email: HSCP.ParticipationEngagement@fife.gov.uk

Telephone: 03451 555 555 Ext 475030

Address: Participation and Engagement Team, 6th Floor, Fife House, North Street, Glenrothes KY7 5LT

The closing date for responses is: 7th April 2024

Thank you for taking the time to complete this form - your feedback is very important.



Section 1

About You

1. We would like to know a bit about you. Are you?

- A parent, carer or guardian of a child or young person who is using/has used ADHD Services?
- Someone who uses ADHD Services for children and young people
- Someone who previously used ADHD Services for children and young people
- Someone who provides ADHD Services for children and young people
- Other – please specify below

Section 2

Your Experiences

We want to understand your experience of ADHD Services and what is important at different points in the journey.

2. What is working well with ADHD Services?

3. What is not working well with ADHD Services?

4. What is important prior to being referred to ADHD services?

- Information about attention-related difficulties
- Information about what the challenges can be
- Information on what you can do to help
- Information on sources of support
- Other – please specify below



5. What is important when being referred to ADHD services?

- Understanding the referral process
- Understanding how the ADHD service works
- Feeling informed about what is happening
- Having someone to contact if things change
- Other – please specify below

6. What is important when waiting for ADHD services?

- Having information about waiting times
- Knowing what's likely to happen when you are seen
- Knowing how to access supports while waiting
- Having someone to contact if things change
- Other – please specify below

7. What is important when receiving ADHD services?

- Feeling listened to and respected
- My family, carer or guardian being supported too
- Having access to the right supports
- Having a named person to coordinate care
- Understanding when you might get appointments
- Other – please specify below

8. What is important when leaving ADHD services (when discharged or moving to adult services?)

- Understanding the process of leaving (or moving)
- Being kept informed about what is happening
- Having a clear plan and supports



- Having someone to contact if things change
- Other – please specify below

9. Thinking about the answers you have given so far, how do services match up to what you feel is important?

- Fully
- Partially
- Not at all

10. Thinking about your answer to question 9, can you say more about your experiences?

11. What changes would improve your experience of ADHD services?

12. Would you like to be informed about the outcome of this survey? If yes, please tell us your name and provide contact details

13. Would you like to be contacted about any future surveys? If yes, please tell us your name and provide contact details

Section 3



2. Which locality area in Fife do you live or work in?

- Cowdenbeath (includes Lochgelly, Kelty and Cardenden)
- City of Dunfermline
- Glenrothes (includes Thornton, Kinglassie and Leslie)
- Kirkcaldy (includes Burntisland and Kinghorn)
- Levenmouth (includes West Wemyss, Buckhaven, Methil, Methilhill, Kennoway and Leven)
- North East Fife (includes Auchtermuchty, Cupar, Taybridgehead, St Andrews, Crail and Anstruther)
- South West Fife (includes Inverkeithing, Dalgety Bay, Rosyth, Kincardine, Oakley and Saline)

Section 4

Equalities, Diversity, and Inclusion

Under the Equalities Act 2010 (Scotland) we continue to work to protect people from discrimination because of: age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity.

We strive to ensure that people who identify with these protected characteristics can participate in any events that are of interest to them.

We will use the information in this section to understand who is responding to our consultation and engagement exercises. The information will help us to ensure we have representation from the broadest set of people within Fife and we are reaching every part of our community.

The information will be used for monitoring and reporting purposes relating to this consultation and for no other reason.

17. Would you like to continue to provide us with feedback to help us better understand who we are engaging with?

- Yes No

18. What is your age?

- Under 18 18-24 25-34 35-44 45-54 55-64
 65 and older Prefer not to say

19. How would you describe your gender?



- Man Woman Trans man Trans woman
 Non-binary Identity not listed Prefer not to say

20. If you would like to specify your identify, please use the following text box

21. How would you describe your sexual orientation?

- Asexual Bi-sexual Fluid Gay man
 Lesbian
 Pansexual Queer Straight / Heterosexual Identity not listed
 Prefer not to say

22. If you would like to specify your sexual orientation, please use the following text box

23. Which of the following best describes your ethnic group or background

- White:
 Scottish *English* *Welsh* *Northern Irish* *Other British*
 Irish
 Polish *Gypsy / Traveller* *Roma* *Showman/*
Showwoman
 Other _____
- Any mixed or multiple ethnic groups
Please write in: _____
- Asian, Scottish Asian or British Asian:
 Pakistani, Scottish Pakistani or British Pakistani *Indian, Scottish Indian*
or British Indian
 Bangladeshi, Scottish Bangladeshi or British Bangladeshi *Chinese, Scottish*
Chinese or British Chinese
 Other
- African, Scottish African or British African
Please write in (for example, Nigerian, Somali): _____
- Caribbean or Black:
Please write in (for example, Scottish Caribbean, Black Scottish): _____
- Other ethnic group:
 Arab, Scottish Arab or British Arab
 Other, please write in:

24. What is your religion or belief?



- None Church of Scotland Roman Catholic Other Christian Muslim
 Hindu
- Buddhist Sikh Jewish Pagan Prefer
not to say

25. Would you describe yourself as having a health condition and / or a disability?

- Yes No Prefer not to say

26. Do you have any of the following, which have lasted, or are expected to last, at least 12 months? (Tick all that apply)

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Full or partial loss of voice or difficulty speaking (*a condition that requires you to use equipment to speak*)
- Learning disability (*a condition that you have had since childhood that affects the way you learn, understand information, and communicate*)
- Learning difficulty (*a specific learning condition that affects the way you learn and process information*)
- Developmental disorder (*a condition that you have had since childhood that affects motor, cognitive, social, and emotional skills, and speech and language*)
- Physical disability (*a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting, or carrying*)
- Mental health condition (*a condition that affects your emotional, physical, and mental wellbeing*)
- Long-term illness
- Disease or condition (*a condition, not listed above, that you may have for life, which may be managed with treatment or medication*)

27. What is your relationship status?

- Single Married Divorced Civil Partnership
Widowed Separated
- Living with a partner Prefer not to say

28. Are you currently breastfeeding, pregnant, or recently given birth?

- Yes No Prefer not to say

29. Please specify if you are:

- Pregnant Breastfeeding Recently given birth Prefer not to say

Thank you for taking the time to complete this form.



Appendix 2 – Stakeholders

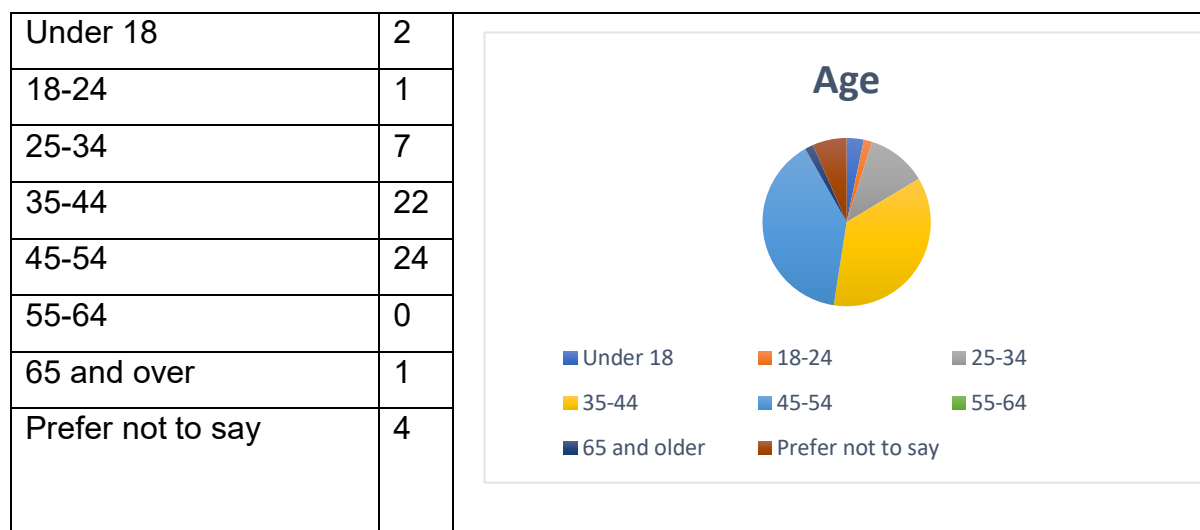
Stakeholder List
Children and young people who use ADHD Services via clinicians and staff
Parents, Carers and Guardians of people who use or have used ADHD Services via clinicians and staff
Staff working within ADHD Services
NHS Fife Website and Social Media
Fife HSCP Website and Social Media
Fife Carers
Fife Young Carers
Kindred Fife
Nourish Centre
John Fergus School
Hyperclub 2012
Fife Gingerbread
Fife Voluntary Action



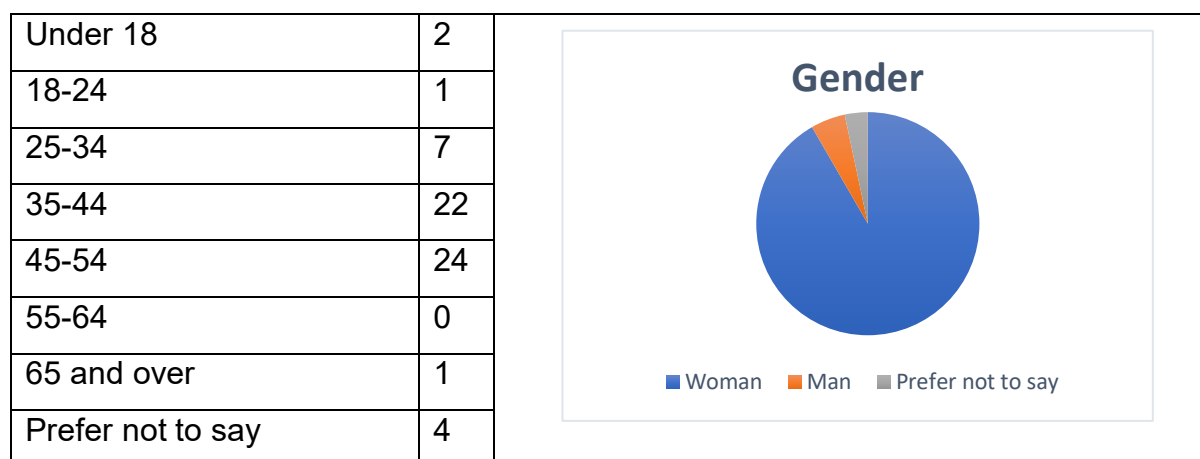
Appendix 3 – Equality, diversity and inclusion data

Of the 108 survey responses received, 61 (56%) people completed the equality, diversity and inclusion questions contained in the survey. Responses are summarised below:

Age

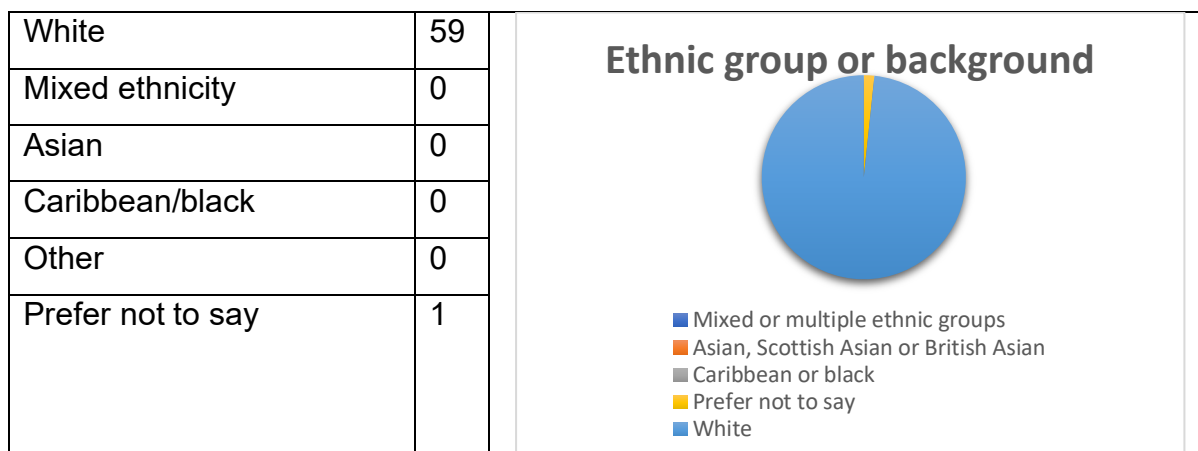


Gender

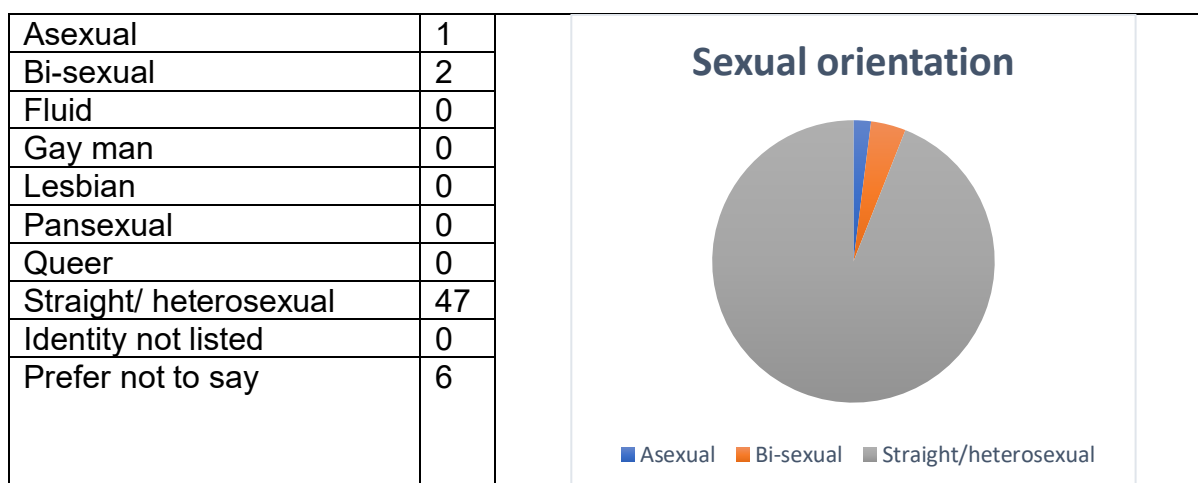




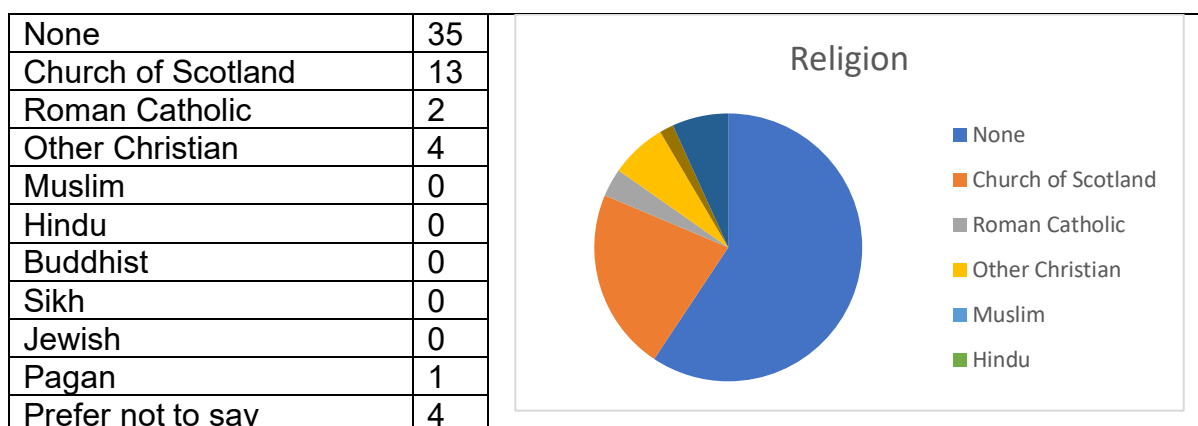
Ethnicity



Sexual Orientation

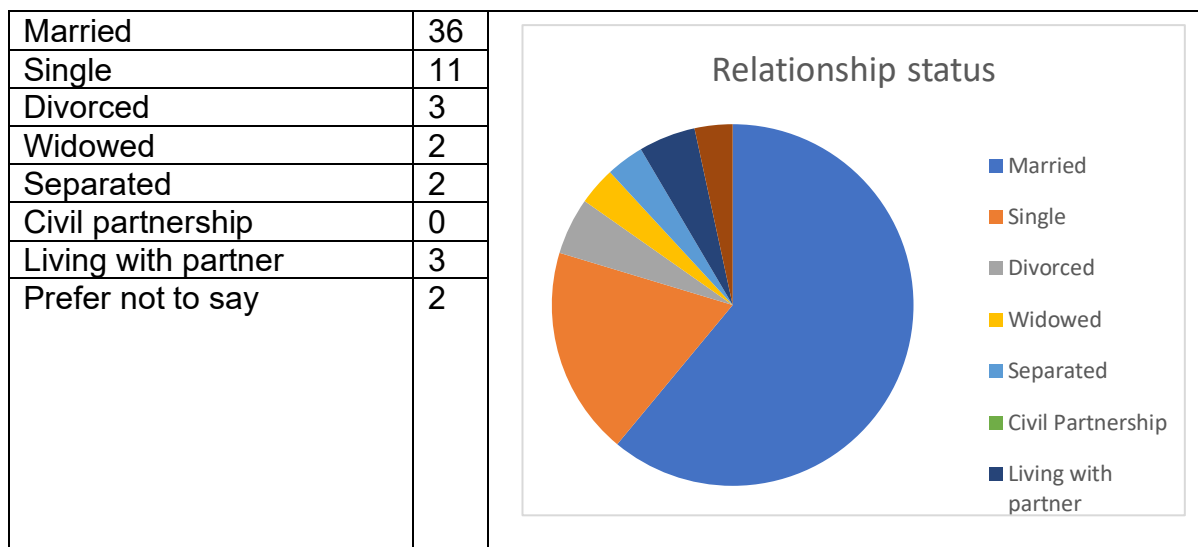


Religion

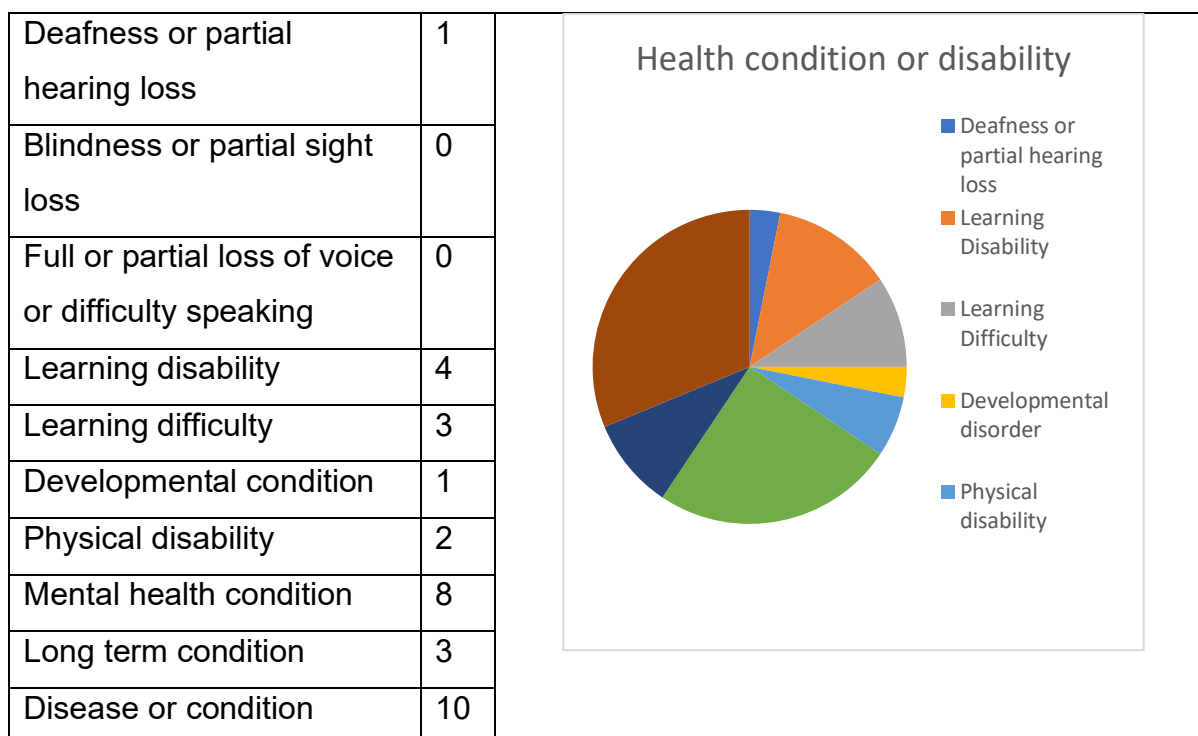




Relationship status

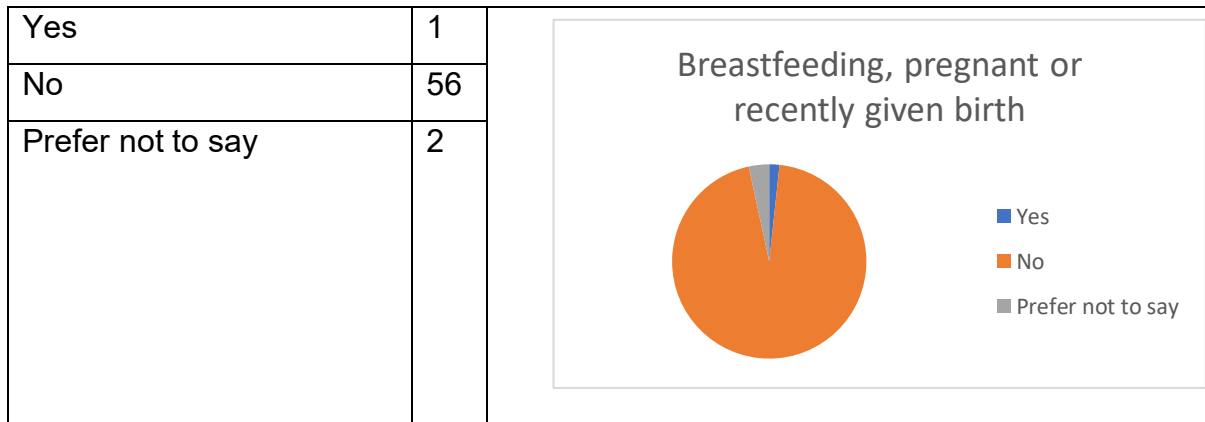


Health condition or disability





Breastfeeding, pregnant or recently given birth





Appendix 4 – Key themes from survey feedback

Waiting Times



A key theme from feedback was that waiting times for assessment, diagnosis, support once diagnosed, receiving medication and for review appointments were too long resulting in families feeling frustrated and under strain. Responses indicate that outcomes for children were being affected while they were waiting

“The assessment process for a diagnosis is too long and there isn’t enough staffing to improve this yet. The children are often older and have trauma from trying to fit in with no diagnosis”.

“The referral process, the diagnosis process, the support systems, the medication, the access and wait times to all of these things”

“Waiting times. Non attendance of patients to their clinics even though they have been contacted prior to their appointment and confirmed”.

“Years of time passing, lives passing by. Wasted time.....Young people find their own way to manage which can be the form of drugs to try and cope all the time creating a big black hole involving every family member. The web of destruction is immeasurable with the painful let down”

“My niece is awaiting assessment for referral it’s not good enough. I am a nurse and can obviously see he needs help and the family”

Reviews and Appointments



Insufficiency of reviews and appointments were a key theme with respondents stating that reviews were not taking place regularly enough and appointments were often cancelled at short notice. One staff response highlighted that there was an inability to meet the ADHD review standards in Tier 2.

“Never heard anything from ADHD nurse after diagnosis and being started on ADHD medication. To monitor my son’s weight and blood pressure. Was meant to be 3 months after starting medication”

“Numerous appointments cancelled at last minute”

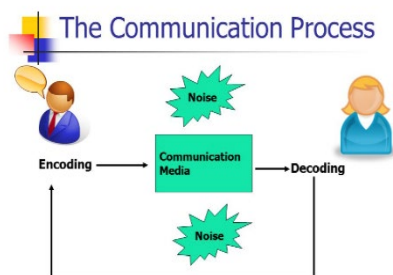
“Shortage of staff so appointments cancelled”



“Impossible to get in contact with anyone. Lack of reviews. Teams contacts with no option to have telephone reviews despite IT issues”

My son was diagnosed and medicated last year, he has been seen once to check his weight and height. That’s all the support we have had”

Communication



A key theme was that a lack of communication between services and families had contributed to the negative experiences of the service. People felt that it could be very challenging speaking to anyone from the service about waiting times and appointments. They also said that they had not received communication about waiting times or the processes involved.

“The service doesn't communicate well with education”

“In our experience, nursing staff don't listen to parents, as the parents are the ones who live everyday with the child”

“Lack of communication between the practitioners, staff and clients”

“Very little communication between services, parents have to repeat their stories and becomes more difficult if receiving some support outwith Fife e.g. if live on the border - there should be better communication between all”

“It's not easy trying to find a way to contact your practitioner when you need to”
“More direct contact information. None of the appointment letters have contact details”



Support

There were several responses about the lack of information to support children, young people and their families who are awaiting assessment and a lack of support for staff who are working with children waiting to be seen, particularly those with lower levels of need. Responses indicate that families can feel overwhelmed and unsupported in trying to manage a child or young person without the right services in place.

“We only had monitoring of medication really and apart from being offered an online course there is nothing to support parents or the child”



“For some families I am working with, they are very supportive and trying their best to support their child at home but the child is so heightened it is incredibly difficult. The family really need support but there is very little out there”

“No focus on psychological support and strategies to manage condition and too much emphasis on medication. Need to consider holistic care and wider support”

“While waiting for assessment no support was available”

Joined up care



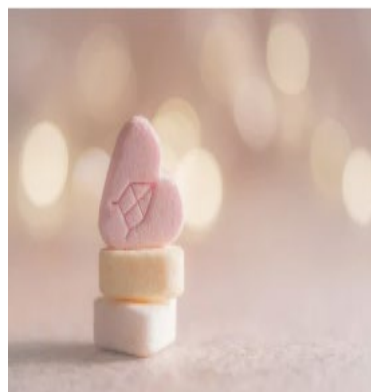
A key theme was the lack of a joined-up approach across services with allied health professionals and non-statutory agencies who are not currently working alongside ADHD Services to support children, young people and their families to access resources and information while waiting. It was also reported that staff in schools and staff who are working with children waiting to be seen would benefit from additional training and support to enable them to do this better and improve outcomes for children.

“Long waits, lack of access to medication, parents Inc Online only, no coaching/training involved. No joined up thinking/multi-professional thinking with AHPs/education staff. no training/support for education staff on referral/diagnosis/support”

“Having allied health professionals and non stat agencies running alongside the team. Services are there but not joined up thinking and sharing of resource”

“Teaching all schools about adhd and how they can help more”

Medication



Some respondents found that the email ordering system works well, while others highlighted that there is confusion about how repeat medication is ordered and issues around obtaining medication from pharmacies. Responses indicate that there are not enough reviews of medication, and appointments to discuss medication for children with a diagnosis are taking too long. Access to medication can be challenging and medication reviews are frequently cancelled which can mean that children are going unmedicated or on the wrong dose.

“Appointments to review medication are frequently cancelled and there is not enough support for the individuals and their carers”



“The medication also has been difficult for some of my families to find. This has been very challenging in high tariff cases where I have had a pupil who has been much more heightened and his presentation in school has drastically escalated. This has been sad to see as things had been much more settled previously”

Access



A key theme is that people are experiencing challenges accessing ADHD services and supports. They report that it is difficult to contact the service and to have referrals accepted from GPs and Education staff. Some respondents have opted to ‘go private’ to get a diagnosis and they then face challenges getting support from ADHD services. Others report that having waited a very long time to be seen, they are then told they do not meet the criteria for the service.

“Refusal to accept referral from GP is ridiculous. I am an experienced support for learning teacher, and my son’s difficulties are present in multiple settings, and yet referral knocked back. This totally dismisses the parents’ opinions and experiences”

“Long wait times, unclear whose responsibility it is to refer a child to testing”

“I cannot make comment on what works well as the service to being referred and diagnosed has been appalling. My daughter who was referred by her GP over 2 years ago, eventually received the disappointing news that she doesn’t meet the “criteria”. This is after lots of episodes of stress and anxiety to chase this up and being sent all around the houses”

“System doesn’t work. We’ve done everything we possibly can over the last two years to support my son. GP referred last June, knocked back and signposted to parenting advice which is patronising and insulting when you have no idea how we parent, and implies that poor parenting is the problem without knowing the full picture. We’re now at a stage where violence is such a daily danger that we’ve booked a private assessment. It shouldn’t be this way”