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Parent/Caregiver Experiences of a CAMHS ADHD Assessment Pathway: A Qualitative Service Evaluation

Emily Kruger[1]

Abstract

Background: Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition characterized by impulsivity, inattention, and hyperactivity. Although the literature has explored the parental impact of living with a child diagnosed with ADHD, less is known about the ADHD assessment journey for children and the parental experiences of this. A recent service evaluation suggested that exploring parental perceptions of a child's ADHD assessment pathway could be beneficial in understanding experiences, gathering ideas for future service development, and collecting service user feedback. **Aims and Objective:** The aims were to (a) explore the broad experiences of parents/caregivers accessing the ADHD assessment pathway for their child and (b) explore experiences of remote appointments during the assessment process in consideration of the COVID-19 pandemic. **Methods:** Twelve parents of children who had experienced an ADHD assessment within a CAMHS pathway participated in a telephone-based semi-structured interview. This involved gathering experiences of the CAMHS ADHD pathway from a parental perspective. The evaluation implemented a qualitative design. Qualitative data was analyzed through thematic analysis. **Results:** Results revealed seven main themes. Regarding general experiences of the pathway, parent/caregiver interview responses indicated a sense of relief, feeling understood, and the service being child-focused during the assessment. Difficulties were highlighted within the themes, such as long waiting lists impacting on the child and parent as well as lengthy assessments. In reference to COVID-19 and remote/telephone appointments, interview responses indicated some positives of having remote appointments, such as comfort and convenience. Thus, the strengths of face-to-face communication were highlighted.

Keywords
ADHD, child assessment, parental ADHD, neurodevelopment

Recommendations

1. To consider ways in which waiting list times could be reduced by possible team expansion, given the negative impact of the waiting lists.
2. To consider ways parents/caregivers can be more supported when they are on the waiting list, for example, through the delivery of support groups, self-help material, and detailed information on the assessment journey.
3. To consider ways children waiting for an assessment could be more supported while on the waiting list, such as offering child support groups or workshops.
4. To consider and review adaptions that can be made throughout different assessments, to ensure both parents and children feel comfortable with the length of assessments.
5. To consider and be aware of the reported benefits of face-to-face appointments identified within this evaluation when considering either remote or face-to-face appointments.
6. The service could consider providing families with the choice as to which option (remote or face-to-face) they would prefer during the assessment.
7. To continue gathering feedback from parents as well as children in view of COVID-19 adaptations to the ADHD assessment process.

Introduction

Attention deficit hyperactivity disorder (ADHD) is a treatable neurodevelopmental condition of brain development,

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characterized by high levels of impulsivity (e.g., acting without thinking, interrupting people), inattention (e.g., being easily distracted, making mistakes), and hyperactivity (e.g., excessive talking, difficulties sitting still) (APA, 2013). With typical onset starting before the age of six, ADHD is believed to affect around one in 20 school-aged children across the world and is widely known to impact an individual's life, academic abilities, and social skills (Faraone et al., 2001). Within the United Kingdom, ADHD in children is typically formally diagnosed following a specialist assessment period within a multidisciplinary team, integrating the clinical views of psychiatry, psychology, education, nursing, and social work staff. It is based on guidelines set by the National Institute for Clinical Excellence (National Institute for Health and Care Excellence (NICE), 2018), which involves information being collected from multiple sources (e.g., the child, parents, and teachers) with different methods of assessment utilized (e.g., interviews, observations, self-report measures) as suggested by multiple clinical practice guidelines (Sayal et al., 2018). The assessment process can also involve the child completing a computerized test known as the QbTest, which combines a test of attention on a computer with the measurement of excessive movement via a camera (Hollis et al., 2018). For this evaluation, the service involved in this project incorporated a similar assessment process (Appendix A). It should be of note that due to the COVID-19 pandemic, this was adapted moderately, as a proportion of appointments were carried out remotely via the telephone to abide by social distancing policies and national guidelines.

Literature exploring ADHD has primarily focused on parental experiences of living with a child with ADHD. Thus, within a systematic review of qualitative research, it was found that parents of children with ADHD experience feelings of guilt, hope, blame, stigmatization, and exhaustion. This highlights the many challenges parents experience while caring for children with ADHD (Laugesen & Groenkjaer, 2015). A more recent study found that parents living with a child with ADHD also experience high levels of stress and impaired social and occupational functioning (Mofokeng & van der Wath, 2017). Research has also started to investigate child experiences of ADHD. To illustrate this, a recent meta-analysis found that from 16 studies analyzed, children with ADHD had a range of challenging experiences linked to psychological abilities, adjusting to needs, accepting self, a lack of belonging, and experiences of forming personal identity (Ringer, 2019). Despite these valuable findings, few studies specifically explore experiences of the ADHD assessment process, leading to a possible diagnosis of ADHD. A relatively recent study based in Denmark aimed to gain a clearer understanding of mothers' experiences of the ADHD diagnostic process for their children (Rasmussen et al., 2021). Within this, mothers reflected on their frustrations with the lack of support during the assessment and following diagnosis, as well as not understanding what to expect from the assessment process for their child. More so, a recent quantitative service evaluation aimed to evaluate an ADHD assessment service for children in terms of referrals made, number of completed assessments, waiting list numbers, and adherence to NICE guidelines. One of the recommendations from this service evaluation was to explore parent perceptions of a child's ADHD assessment, with view of generating useful suggestions for possible service development and improvement (Barnes et al., 2020). As evidenced, the literature is sparse regarding qualitative experiences of the ADHD assessment process, proving it difficult to thoroughly evaluate, develop, and improve service outcomes for both children and their families. It is proposed that in order to understand and further improve health services, service evaluations should be completed within routine practice as part of the clinical psychologist role (Price, 2019) as this research can lead to positive impact on real-world services. In view of this, the current evaluation focused on parent/caregiver experiences of the ADHD assessment process for their child. It is argued that this service evaluation has the potential to fill a gap in the research which has not yet been explored, prompting the need to evaluate service pathways in order to understand their various strengths, limitations, and possible improvements for the future.

Aims and Objective

The aims of this service evaluation project were to (a) explore the general experiences of parents/caregivers accessing the ADHD assessment pathway for their child and (b) explore experiences of remote appointments during the assessment process in consideration of the coronavirus pandemic and future service development.

Method

The Service

The service is based in an outpatient child and adolescent mental health service (CAMHS), specializing in the assessment and diagnosis of ADHD within a South Yorkshire NHS Trust. Within this, there is an assessment team consisting of two principal clinical psychologists and two assistant psychologists. Referrals are generally made by the local community pediatric pathway via a General Development Assessment (GDA) and will be discussed within the ADHD weekly team meeting. Following this, a child is observed in school; a family interview will take place where a developmental history is taken, followed by an assessment to assess a child's attentional skills. The post-diagnostic team encompasses an ADHD nurse, clinical support worker, occupational therapist, and psychiatrist, whereby parent support groups are offered, as well as the option for pharmacological alternatives (see Appendix A for a structure of the pathway process).

Since March 2020, the service has responded to infection control guidelines in view of the COVID-19 pandemic by offering fewer face-to-face and more telephone appointments where possible. For example, parent interviews have been conducted over the telephone to reduce unnecessary contact and social mixing.

Data Collection

Between January and March 2022, 12 parents whose child was recently assessed by the CAMHS ADHD pathway within a South Yorkshire Trust took part in a semi-structured telephone interview. Participants were selected through purposive sampling (Patton, 1990), in order to capture the most appropriate individuals who could answer the interview questions in relation to their ADHD pathway experience. Braun and Clarke (2013) suggest that for a small-scale project, 6 to 10 participants are recommended for interviews; therefore, 12 participants for the current project felt more than satisfactory. The interview was centered around general experiences of having a child assessed on the pathway, as well as questions relating to remote appointments. Interviews lasted approximately 30 minutes and took place during the working day between 9 am and 5 pm. Participants were asked to self-select and volunteer for the evaluation upon initial telephone contact.

Design

This project employed a qualitative research design, whereby parents were invited to participate in a semi-structured telephone interview facilitated by the writer. In order to gather experiences of the ADHD assessment process for parent/carers, I and the project commissioners felt that the most rich and effective way to do this would be to gather qualitative data via interview. Semi-structured interview is well known to be the most exemplary technique within the qualitative data collection arena, striking a balance between focus and flexibility (Smith & Osborn, 2003). It was felt by both the researcher and commissioners that quantitative methodologies would not be the most suitable approach to address the research question due to the exploration of complex issues (Burman, 1994).

Materials

The semi-structured interview topic guide (Appendix B), information sheet (Appendix C) and consent form (Appendix D) were designed in collaboration with the commissioners within the ADHD team, including the principal clinical psychologists who also acted as the ADHD pathway leads. Regular meetings took place to review the materials as a team and make the necessary changes before data collection commenced. Appendix E presents the agreement for the project to commence. Commissioners also agreed to future publication of the project (Appendix F).

Procedure

The parent/carer of each child was initially contacted by telephone and asked if they would like to take part in the service evaluation project. Next, the information sheet was read to them over the telephone to provide initial context to the project (Appendix C). If a parent agreed to participate, they were asked if they wished to partake at the time of the initial telephone call or be contacted at another time of their convenience. Following this, an online consent form was read to each parent over the telephone (Appendix D) and signed electronically. Each semi-structured telephone interview was audio recorded using a secure device provided by the service and transcribed the same day by the writer. Following this, each recording was erased from the secure device. In summary, each interview was transcribed, anonymized, and analyzed by the writer using thematic analysis techniques (Braun & Clark, 2006).

Analysis

Thematic analysis was chosen as the method in which data would be interpreted as part of this service evaluation. Thematic analysis is a tool commonly used as a coherent way to identify patterns in meaning across qualitative data in relation to specific questions (Braun & Clarke, 2006). Deriving from a more constructionist paradigm, thematic analysis provides the researcher flexibility in its approach, providing rich accounts of multifaceted data (King, 2004). It is also reported that thematic analysis can be a valuable approach to adopt when examining the perspectives of different participants, highlighting similarities and differences across numerous other insights (King, 2004). Most importantly, thematic analysis is commonly used to detect recurring patterns in a collection of qualitative data, capturing important information relating to the area of interest. Although phenomenological methods of analysis were considered as part of the planning stage, it was felt that the aims of the service evaluation fit better with thematic analysis due to wanting to understand and explore experiences, compared to interpreting meaning and sense-making (Willig, 2008). Thus, the six-step method coined by Braun and Clarke (2013) was utilized during this process (see Figure 1). The analysis was inductive in its methodological stance, whereby it was data driven. Further information on the thematic steps can be found within Braun and Clarke (2013). Each transcript was transcribed by the researcher and additionally checked against the audio files for further accuracy

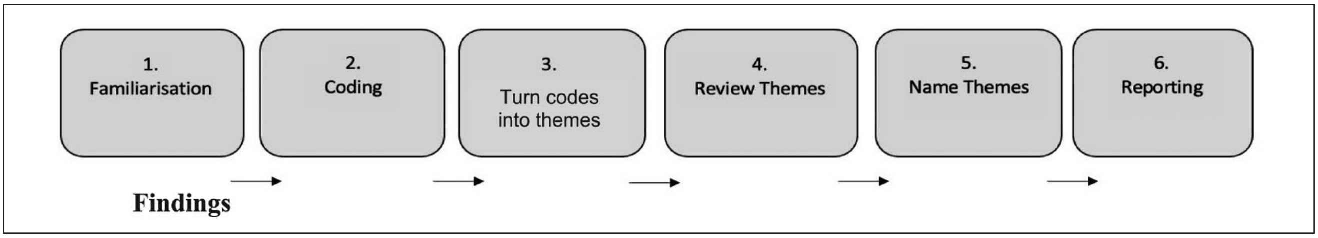


Figure 1. Thematic analysis outline.

Table 1. Visual Representation of the Themes.

Parent/caregiver general assessment experiences	Parent/caregiver remote assessment experiences
Theme 1–Waiting	*Theme 6*–Flexibility of the process
Subtheme–Parent/caregiver impact	Subtheme–Comfort
Subtheme–Child impact	Subtheme–Convenience
Theme 2–Sense of relief	*Theme 7*–Consequences to communication
Subtheme–Assessment outcome	Subtheme–"Face to a name"
Subtheme–No more waiting	Subtheme–"Full picture"
Theme 3–Feeling heard	
Theme 4–Child-focused	
Theme 5–Lengthy assessments	

and familiarization. Each transcript was then coded by hand by the researcher, whereby codes were used to help identify the main themes among the data. Upon reviewal, a meeting was held with the commissioners in the ADHD team to discuss the main themes jointly. Discussion was aided by additional reflective notes made by the researcher at the time of the interview. Themes, along with subthemes, were then named jointly by the researcher and discussed with the commissioners to ensure that the story of the theme was captured within its label. Triangulation of the data occurred, whereby the themes were reviewed by a trainee clinical psychologist independent to the evaluation, and changes were agreed upon and made accordingly.

Credibility

To establish rigor, various methods were used in order to ensure this (Thomas & Magilvy, 2011). Firstly, direct quotes from the participants have been used in this report, which also assisted with naming some of the themes during the analysis. In addition, the triangulation of data allowed for an independent individual to review the themes and suggest areas for change and improvement. Finally, notes were taken and kept during the data collection phase, which allowed for comparison with the data and assisted in developing the themes.

Findings

Initial codes were firstly identified from the data gathered from the telephone interviews. Thus, analysis of interview data identified seven themes, with subthemes incorporated as part of four of these. For ease and clarity, these themes have been organized into general experiences of the pathway and experiences of remote appointments (telephone). A visual representation of the themes and subthemes is made available in Table 1. Themes and subthemes are described below.

Parent/Caregiver General Assessment Experiences

Theme 1—Waiting

All participants from the interviews spoke of a lengthy wait for the assessment process to start for their child, with a general sense of having to sit with unanswered questions for a long time. This theme has been organized into two subthemes: parent/caregiver impact and child impact of the wait.

Parent/Caregiver Impact. Participants spoke of various impacts of the long wait time before the assessment started for their child and how this affected them.

> Err, I had to wait a while for my child to be seen which was hard to wait for and sit with. (Participant 1)

> It's the amount of time it takes for your child to be seen, it just takes so long and feels frustrating as a parent. (Participant 3)

> It just took a long time, waiting for the appointments to come, he was waiting from the age of five and he's seven now, it is hard to sit with. (Participant 12)

Child Impact. Three participants spoke of how the length of wait for assessment had a negative impact on their child at the time.

> It just took years of waiting which can have quite a negative impact on your child at school. (Participant 2)
>
> My child had such a long wait and because he's older now he is suffering more and noticing it more before support could be offered. (Participant 9)

Theme 2—Sense of Relief

Ten participants spoke of a sense of relief, either once the assessment process had commenced for their child or after receiving the outcome at the end of the assessment. This has therefore been organised into two subthemes: assessment outcome and no more waiting.

Assessment Outcome

> It was nice to finally get an answer and the relief is unreal in a way, it is a mix of emotions but just finding the outcome was relieving. (Participant 9)
>
> Getting the diagnosis was positive, it was just good to finally know. (Participant 3)

No More Waiting

> I'm not an expert in this field but it seemed my child had a problem, so it was a relief when the assessment was started. (Participant 2)
>
> It just felt good to know we were finally getting the ball rolling. (Participant 1)

Theme 3—Feeling Heard

Eight of the participants spoke of feeling heard and listened to during the assessment process, when given the opportunity to share their concerns as parents/carers. It appeared that overall, this was a positive experience for many participants.

> All of my concerns were thoroughly listened to. (Participant 4)
>
> When I started to talk, I just don't stop but she listened to everything and let me get on with it, with no interruptions. (Participant 10)
>
> People listened to me, and understood what I was going through, so it felt really nice. (Participant 12)

Theme 4—Child-Focused

Three participants described a sense of feeling as though the assessment process was very person-centred and focused on the individual child being assessed.

> The team really took the time to get to know my child and find out their individual difficulties. (Participant 4)
>
> They make the kids feel they are the most important person in the room, really understanding. (Participant 6)
>
> They really listened and put my child first. (Participant 12)

Theme 5—Lengthy Assessments

Four participants reflected on some difficulties with the length of some of the assessments which was challenging.

> Yeah . . . I had a 3-hour phone assessment, it just felt, well, it's a little bit long really for an appointment really. (Participant 5)
>
> Some of the appointments were, I guess, long for my child and me to sit through, it might be good to break some of the assessments down. (Participant 2)

Parent/Caregiver Remote Assessment Experiences

Two themes were highlighted from the data in relation to remote assessment experience: flexibility of the process and consequences to communication. From the interview data, all participants had experience of some form of remote assessment. For most of the participants, remote appointments included information gathering from parents over the telephone as well as the delivery of assessment feedback to parents over the telephone.

Theme 6—Flexibility of the Process

The first theme highlighted for this section was in relation to the flexibility of remote appointments and the positive aspects of this This was split into the subthemes of "comfort" and "convenience" due to the information collected through interviews.

Comfort. Three participants spoke of feeling comfortable in their own home environment when accessing remote assessments, which appeared to make the process easier for them.

> I think you should do telephone/remote appointments still, it's a good choice to have. Parents can feel worried so it can be helpful to be in your own home feeling comfortable. (Participant 6)
>
> Getting to appointments and finding parking can be stressful, so having assessments from your own home, it just feels more comfortable feels good yknow. (Participant 2)

Convenience. Six of the participants reflected on how remote appointments felt easier, more convenient and a lot quicker in terms of the assessment process.

> It felt very quick and simple to do an assessment over the telephone. (Participant 1)

> You didn't have to go out, so you were at home, and umm it felt quite flexible in that respect, so I think more things could be offered that way going forward. (Participant 2)

> I did like the telephone appointments, it just felt quick. I think that should carry on, especially when the child does not need to be seen physically, everything just feels more efficient. (Participant 7)

Theme 7—Consequences to Communication

Five of the participants indicated a strong preference for face-to-face appointments with clinicians instead of remote appointments. This tended to be centered around being able to see the person in front of them. Secondly, participants also reflected on a preference for face-to-face appointments to get "the full picture."

"Face to a Name". Participants described a preference for putting a face to a name in terms of appointments with professionals.

> Well, you can't put face to names, and you can't pick up on non-verbal cues or signals which is a bit harder. (Participant 2)

> I think face to face is better, I like to see someone face to face because it helps to understand things better. (Participant 12)

"Full Picture". Four participants indicated a preference for face-to-face appointments for professionals to get the "full picture." Participants thus indicated a preference for face-to-face appointments to understand things better for themselves.

> I don't think professionals can get the full picture over the phone sometimes, I think face to face is needed. (Participant 1)

> I think it's hard to get all child behaviours across over the phone or a video screen, so I think continue with face-to-face appointments to get an accurate diagnosis. (Participant 2)

> When its telephone, you put the phone down and think damn, I didn't ask that question and it's over, but if its face to face it will likely come back to you. (Participant 11)

Discussion

The aim of this evaluation was to explore parent/caregiver experiences of the ADHD assessment pathway, as well as experiences of remote appointments during the assessment process. This was an essential area for the team to investigate, considering that the service had not been evaluated before, as well as the recent adaptions made to ADHD assessments because of the COVID-19 pandemic. Thus, as part of the role as a clinical psychologist, it is best practice for services to be evaluated in terms of their delivery, effectiveness as well as development needs in order to understand how to best improve ADHD assessment services for families.

Regarding the general experiences of the ADHD assessment pathway for parents and caregivers, all participants reflected on how the significant wait time for the ADHD assessment to commence was a challenge, whereby parents reported this negatively impacting them and their child. On reviewing the literature, this appears to be a reported challenge among ADHD services for children on a national scale (Lynch & Hedderman, 2006; Roughan & Stafford, 2019), with an imbalance between demand for assessment and staff capacity. In further discussion of the findings, many parents spoke of experiencing a sense of relief, either once the assessment had started or after an assessment outcome was delivered to them. Thus, contrary to the research by Rasmussen et al. (2021), a proportion of parents/caregivers also highlighted additional strengths to the ADHD assessment process, such as being child-focused, and feeling as though they were being listened to and heard during the assessments. However, several participants highlighted some challenges with the assessments, whereby some of the appointments have been reported to be quite long for a child as well as a parent to attend. Regarding the challenges of lengthy assessments, it feels crucial for the ADHD pathway to be aware of this feedback and consider ways in which assessments can be adapted and shaped, dependent on client need. In view of supporting families, finding ways to reduce waitlist times could significantly benefit both parents and their child. It may be helpful for the ADHD team to discuss these findings with relevant professionals regarding future service development and planning. In view of supporting families during the difficult waiting list phase, it may be beneficial to provide parents and their children with extra support during this time, such as providing self-help management strategies dependent on need, support groups, as well as detailed information on the assessment journey. Providing this support could help both children and parents feel less negatively impacted by the wait time. This finding is in line with previous evaluations, whereby parents did not feel as though enough information was given to them about the assessment journey (Rasmussen et al., 2021).

In terms of the themes relating to COVID-19 and remote ways of working, parents and caregivers generally reflected on the positives as well as the difficulties of remote appointments. Many participants reported how remote appointments offered a degree of flexibility during the assessment, allowing parents to feel more comfortable during the process. As many families will have experienced a long wait before the start of the ADHD assessment, it feels imperative for the service to be aware of ways in which the assessment journey can be made easier for families. As well as these positives, many participants also reflected on how face-to-face communication is the preferable option, to put a "face to a name" and improve the richness of the assessment. Due to the ever-changing course of the pandemic and restrictions, it feels essential for the service to continually review COVID-19 adaptations through completing evaluations and additional ways of gathering feedback. However, the strengths and challenges of remote appointments have been clearly highlighted.

Critique

A strength of this review is the fidelity of the results, whereby rigor was maintained and developed by an independent researcher reviewing the data (Maher et al., 2018). However, there are several limitations to consider as part of this project. Firstly, this review took place within one team in a specific location. It is therefore important to consider that the findings may not be generalizable to other teams and the experiences of others. Moreover, the telephone interviews were conducted by a trainee clinical psychologist within the team at the time of the project, therefore it may have been a possibility that participants felt unable to be entirely honest about their experiences of the ADHD assessment process. In view of further methodological limitations, participants may have found it more difficult to form a connection with the interviewer since the interview took place over the telephone rather than face to face. This could have also affected participants' ability to feel safe and comfortable to disclose more personal reflections. Despite the richness of this review, the evaluation has not captured children's experiences of the ADHD assessment process. Further exploration of this could provide the team with additional areas for service development and improvement from a different perspective.

Dissemination

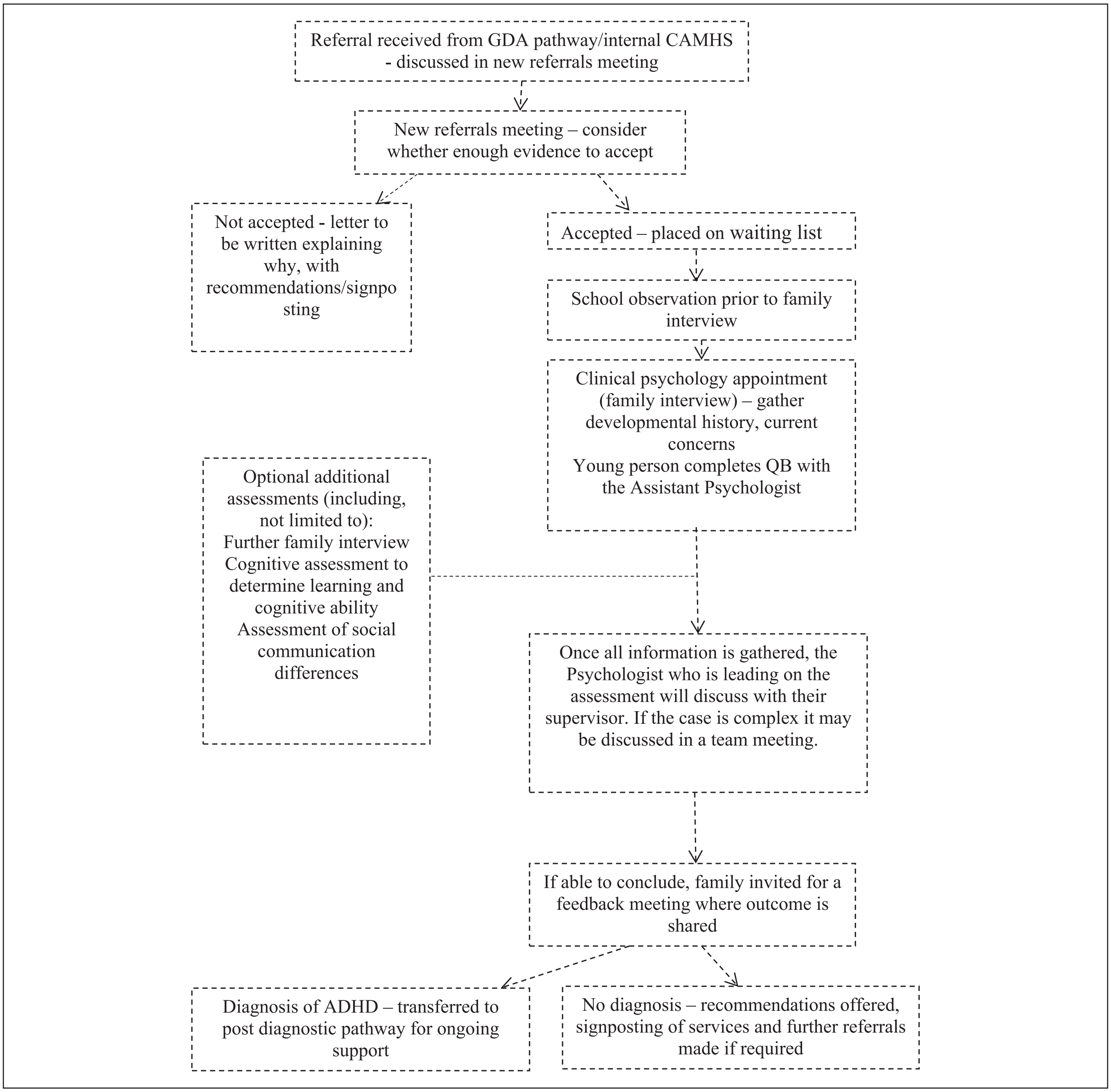
The results of this service evaluation have been presented to the ADHD assessment team, including the commissioners of the review. Dissemination was through a virtual PowerPoint presentation (Appendix G).

Considerations

1. To consider ways waiting list times could be reduced by possible team expansion, given the negative impact of the waiting lists.
2. To consider ways parents/caregivers can be more supported when they are on the waiting list, for example, through the delivery of support groups, self-help material and detailed information on the assessment journey.
3. To consider ways children waiting for an assessment can be more supported while on the waiting list, such as offering child support groups or workshops.
4. To consider and review adaptions that can be made throughout different assessments, to ensure both parents and children feel comfortable with the length of assessments.
5. To consider and be aware of the reported benefits of face-to-face appointments identified within this evaluation when considering either remote or face-to-face appointments.
6. The service could consider providing families with the choice as to what option (remote or face-to-face) they would prefer during the assessment process.
7. To continue gathering feedback from parents as well as children in view of COVID-19 adaptations to the ADHD assessment process.

Appendices

Appendix A—Pathway Referral and Assessment Structure



Appendix B—Interview Topic Guide

1. Thinking about your experience, what was positive about your experience of the ADHD assessment pathway?
   - *what went well?*
   - *what did you like?*
   - *was anything useful?*
2. Thinking about your experience, what was negative about your experience of the ADHD assessment pathway?
   - *did anything challenging happen?*
   - *was anything hard about your experience?*

3. Was there anything that might have improved your experience of the ADHD assessment pathway?
   - what could have made it better?
4. The pathway has been adapted throughout the COVID-19 pandemic to allow for more remote appointments—what has been your overall experience of remote appointments?
   - what are telephone appts like?
5. What has been positive about having remote appointments?
6. What has been more challenging about having remote appointments?
7. After the COVID-19 pandemic ends, could you tell me what you feel should stay the same about the service?
8. After the COVID-19 pandemic ends, could you tell me what think could change about the service?
9. Is there anything else you would like to feedback about the service?
   - anything in general, for example, appointments, buildings, staff

Appendix C—Information Sheet

The
University
Of
Sheffield.

[redacted]

University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane, Sheffield S1 2LT, UK

PARTICPANT INFORMATION SHEET

Invitation

You are being invited to take part in a service evaluation within [redacted] as part of reviewing the current ADHD assessment pathway. We are keen to gain insight into your experiences as a parent/carer, of your child's assessment on the pathway.

Project Background and Aims

The aim of this service evaluation is to understand the parent/carer experience of the ADHD assessment pathway, which will enable the team to consider feedback when changing or developing the service further. It is best practice to gather feedback from service users and their families, to inform service development. We hope to capture your experience through a semi-structured interview.

What the Project Involves

If you choose to participate, this will involve engaging in a semi-structured interview relating to your experience of the assessment process for your child. This will take place via the telephone and will last approximately 15 to 30 minutes. The interview will be audio recorded, to allow for transcribing at a later date.

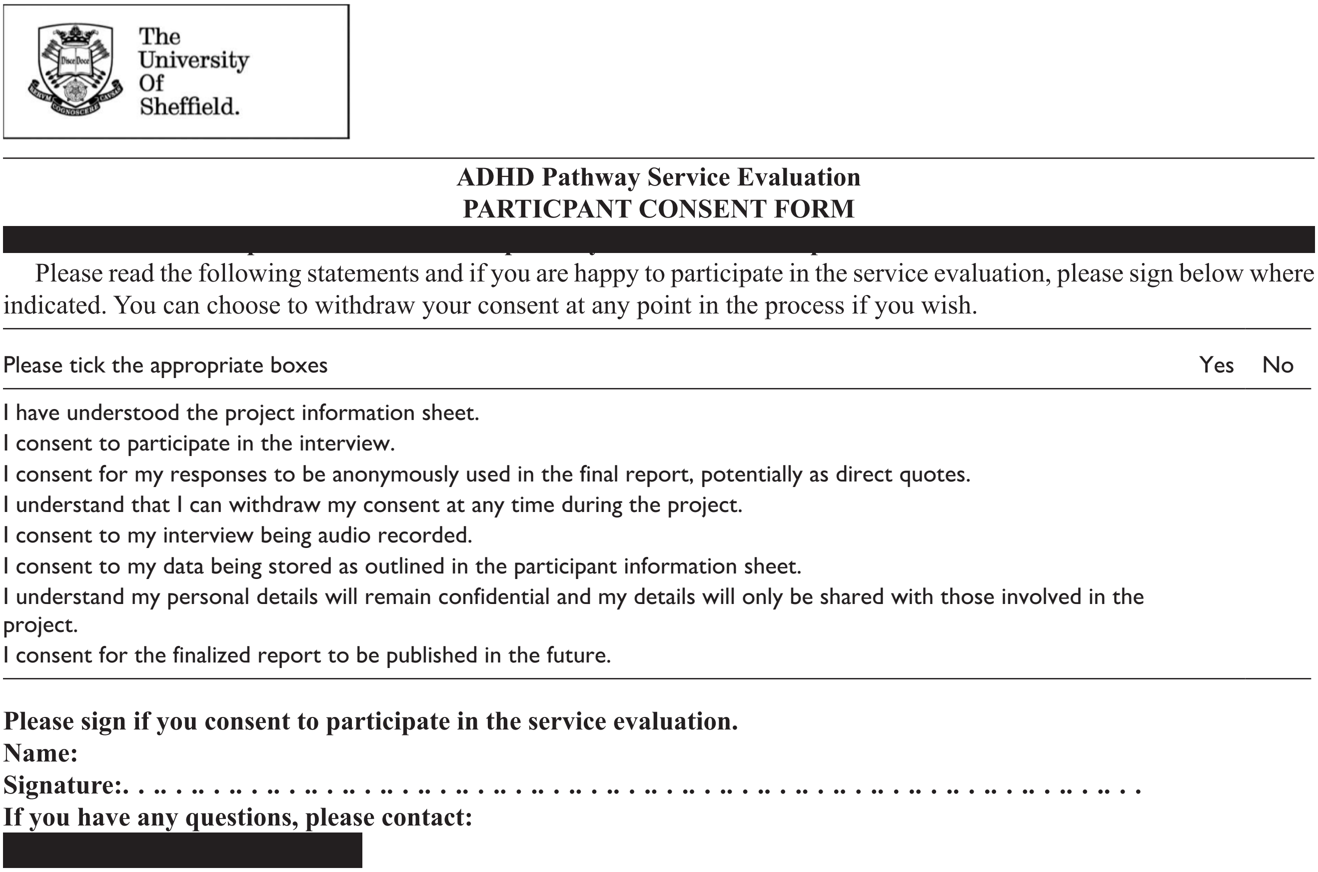
Do I Have to Take Part?

Participation within the evaluation is voluntary. You may decide not to participate. If you choose to participate, you can withdraw your information at any time.

How Will My Data Be Stored?

All data will be stored on a secure university electronic drive. Anonymous responses will be used in the report to illustrate the findings. The report itself will be kept in a secure university drive.

Appendix D—Consent Form



The University Of Sheffield.

ADHD Pathway Service Evaluation
PARTICPANT CONSENT FORM

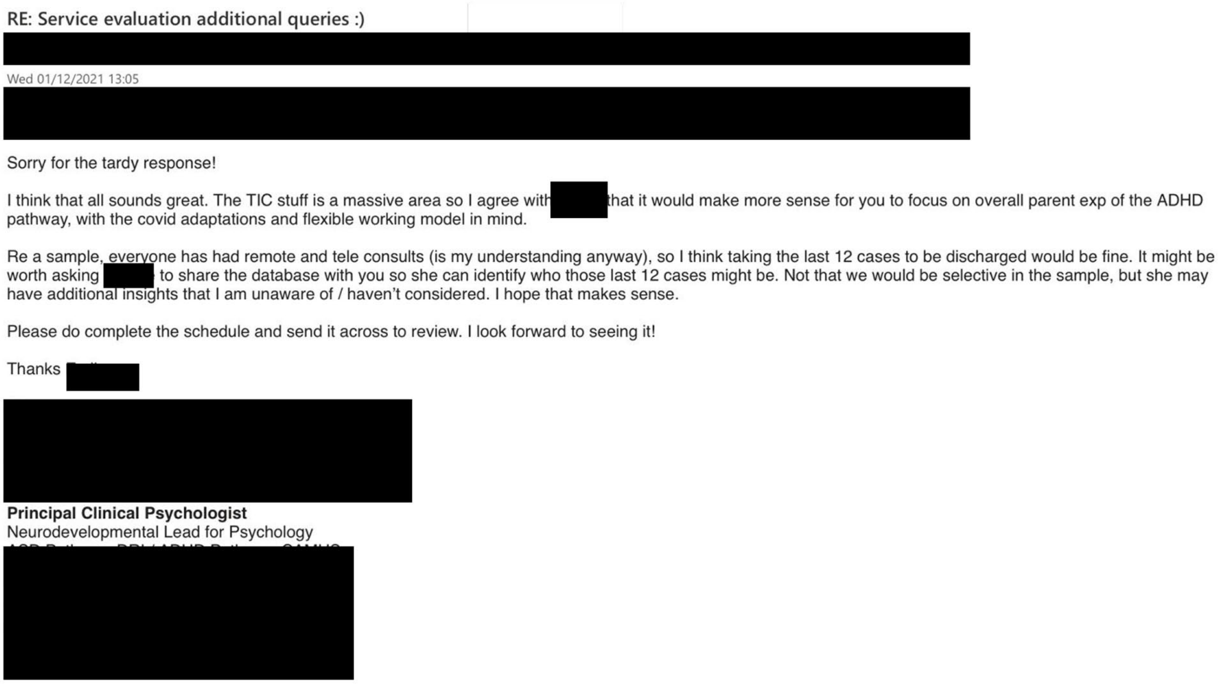
[redacted]

Please read the following statements and if you are happy to participate in the service evaluation, please sign below where indicated. You can choose to withdraw your consent at any point in the process if you wish.

Please tick the appropriate boxes	Yes	No
I have understood the project information sheet.		
I consent to participate in the interview.		
I consent for my responses to be anonymously used in the final report, potentially as direct quotes.		
I understand that I can withdraw my consent at any time during the project.		
I consent to my interview being audio recorded.		
I consent to my data being stored as outlined in the participant information sheet.		
I understand my personal details will remain confidential and my details will only be shared with those involved in the project.		
I consent for the finalized report to be published in the future.		

Please sign if you consent to participate in the service evaluation.
Name:
Signature:. .. ..
If you have any questions, please contact:
[redacted]

Appendix E—Email Providing Approval for the Project to Commence



RE: Service evaluation additional queries :)

[redacted]

Wed 01/12/2021 13:05

[redacted]

Sorry for the tardy response!

I think that all sounds great. The TIC stuff is a massive area so I agree with [redacted] that it would make more sense for you to focus on overall parent exp of the ADHD pathway, with the covid adaptations and flexible working model in mind.

Re a sample, everyone has had remote and tele consults (is my understanding anyway), so I think taking the last 12 cases to be discharged would be fine. It might be worth asking [redacted] to share the database with you so she can identify who those last 12 cases might be. Not that we would be selective in the sample, but she may have additional insights that I am unaware of / haven't considered. I hope that makes sense.

Please do complete the schedule and send it across to review. I look forward to seeing it!

Thanks [redacted]

[redacted]

Principal Clinical Psychologist
Neurodevelopmental Lead for Psychology

[redacted]

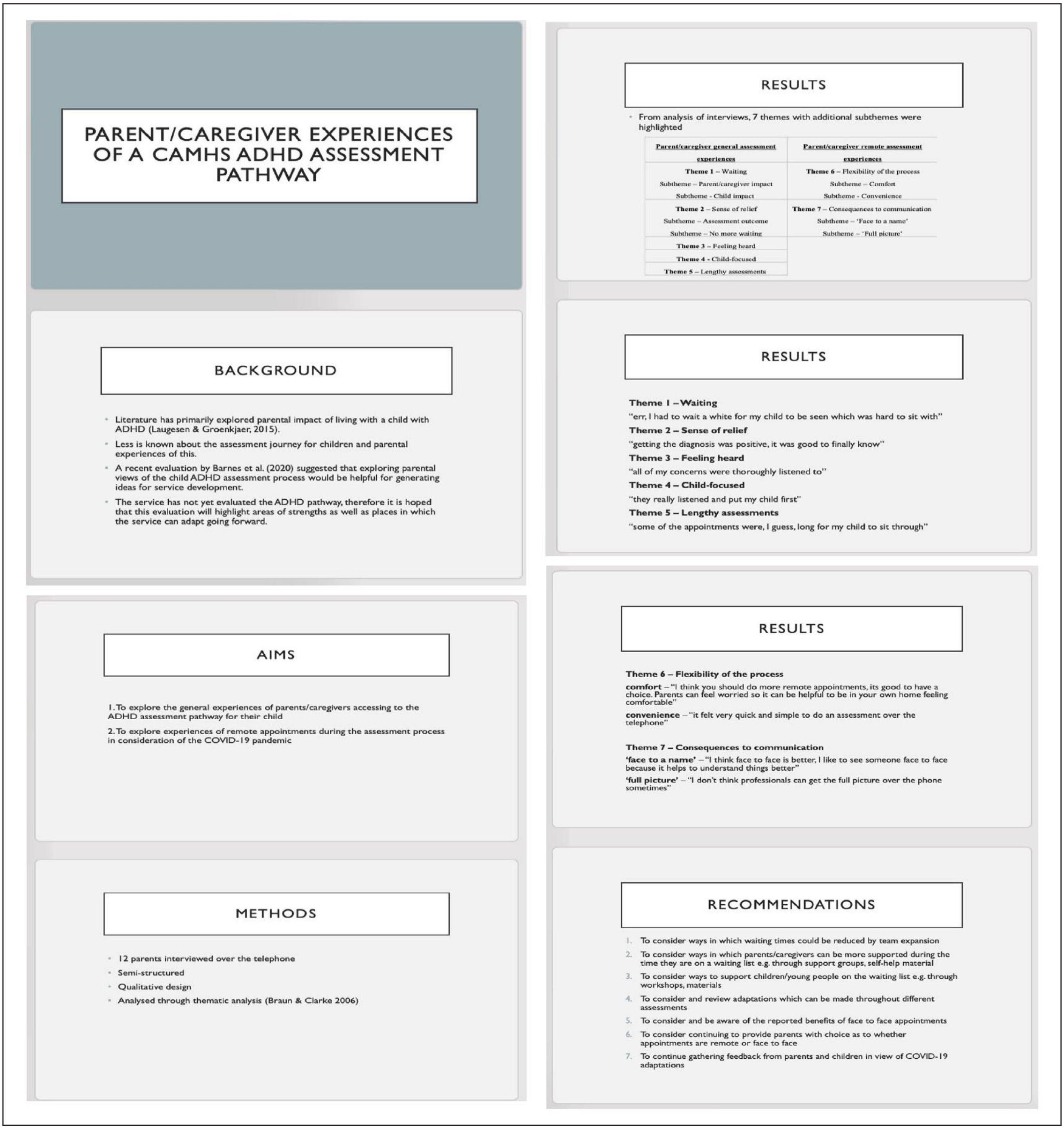
Appendix F—Statement of Agreement for Project Dissemination/Publication

Service Evaluation Project—Document Dated: 21/04/2022

Approval for future dissemination of the findings of the service evaluation is granted.

Typed by:
Dr [redacted] *(Principal Clinical Psychologist).*

Appendix G—Presentation for Dissemination - Parent/Caregiver Experiences of a CAMHS ADHD Assessment Pathway



PARENT/CAREGIVER EXPERIENCES OF A CAMHS ADHD ASSESSMENT PATHWAY

BACKGROUND

- Literature has primarily explored parental impact of living with a child with ADHD (Laugesen & Groenkjaer, 2015).
- Less is known about the assessment journey for children and parental experiences of this.
- A recent evaluation by Barnes et al. (2020) suggested that exploring parental views of the child ADHD assessment process would be helpful for generating ideas for service development.
- The service has not yet evaluated the ADHD pathway, therefore it is hoped that this evaluation will highlight areas of strengths as well as places in which the service can adapt going forward.

AIMS

1. To explore the general experiences of parents/caregivers accessing to the ADHD assessment pathway for their child
2. To explore experiences of remote appointments during the assessment process in consideration of the COVID-19 pandemic

METHODS

- 12 parents interviewed over the telephone
- Semi-structured
- Qualitative design
- Analysed through thematic analysis (Braun & Clarke 2006)

RESULTS

- From analysis of interviews, 7 themes with additional subthemes were highlighted

Parent/caregiver general assessment experiences	**Parent/caregiver remote assessment experiences**
Theme 1 – Waiting Subtheme – Parent/caregiver impact Subtheme - Child impact	**Theme 6** – Flexibility of the process Subtheme – Comfort Subtheme - Convenience
Theme 2 – Sense of relief Subtheme – Assessment outcome Subtheme – No more waiting	**Theme 7** – Consequences to communication Subtheme – 'Face to a name' Subtheme – 'Full picture'
Theme 3 – Feeling heard	
Theme 4 - Child-focused	
Theme 5 – Lengthy assessments	

RESULTS

Theme 1 – Waiting

"err, I had to wait a white for my child to be seen which was hard to sit with"

Theme 2 – Sense of relief

"getting the diagnosis was positive, it was good to finally know"

Theme 3 – Feeling heard

"all of my concerns were thoroughly listened to"

Theme 4 – Child-focused

"they really listened and put my child first"

Theme 5 – Lengthy assessments

"some of the appointments were, I guess, long for my child to sit through"

RESULTS

Theme 6 – Flexibility of the process

comfort – "I think you should do more remote appointments, its good to have a choice. Parents can feel worried so it can be helpful to be in your own home feeling comfortable"

convenience – "it felt very quick and simple to do an assessment over the telephone"

Theme 7 – Consequences to communication

'face to a name' – "I think face to face is better, I like to see someone face to face because it helps to understand things better"

'full picture' – "I don't think professionals can get the full picture over the phone sometimes"

RECOMMENDATIONS

1. To consider ways in which waiting times could be reduced by team expansion
2. To consider ways in which parents/caregivers can be more supported during the time they are on a waiting list e.g. through support groups, self-help material
3. To consider ways to support children/young people on the waiting list e.g. through workshops, materials
4. To consider and review adaptations which can be made throughout different assessments
5. To consider and be aware of the reported benefits of face to face appointments
6. To consider continuing to provide parents with choice as to whether appointments are remote or face to face
7. To continue gathering feedback from parents and children in view of COVID-19 adaptations

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Statement of Contribution

The researcher designed, implemented, and analyzed all aspects of this qualitative service evaluation report. They designed the dissemination documents in collaboration with the project commissioner in the service.

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