

Evaluation of an online follow-up clinic in a children's autism assessment pathway: caregivers' experiences and clinicians' views.

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1. Introduction

1.1 Background

1.1.1 Autism

Autism is characterised as a neurodevelopmental disorder that commonly underlies differences in social understanding and communication, unusually intense interests and/or repetitive behaviours (World Health Organization, 2019). Approximately 1% of the population are autistic, although this is considered to be a conservative estimate as there will be a number of autistic individuals who have not received a diagnosis (Underwood et al., 2021).

1.1.2 Post-diagnostic support

There is growing evidence that unmet needs associated with autism can have serious long term consequences, including increased risk of mental health difficulties and suicide (Cassidy et al., 2014). Timely intervention and family support is associated with improved health and education outcomes for autistic children (Zwaigenbaum et al., 2013), and is recommended in best practice guidelines (National Institute for Health and Care Excellence, 2017). However, current support provision for autistic children and their families is sparse. There are very few evidence-based post-diagnostic interventions available, and families report feeling of isolated following their child's assessment (Galpin et al., 2018).

The National Autistic Society has licensed psychoeducation programmes (Early Bird, Early Bird Plus and Teen Life) for parents of autistic children (NAS, 2023), following which some parents have reported reduced stress and increased confidence (Halpin et al., 2011; McCauley, 2010). However, a recent scoping review of 18 articles concluded that further experimental research is needed to evidence the efficacy of these programmes (Dawson-Squibb et al., 2019). Leadbitter et al. (2022) acknowledged the lack of robustly evidenced interventions in their protocol paper and they outlined an ongoing randomised controlled trial of a post-diagnostic parent support programme (REACH-ASD) incorporating psychoeducation and acceptance and commitment therapy approaches.

Research into family experiences of post-diagnostic support from services tends to be embedded in the wider research into autism assessment processes, with only a few

studies focusing solely on the support and intervention following diagnosis (Hasson, 2019; Legg & Tickle, 2019). The existing evidence base indicates that lack of post-diagnostic support, including inadequate information and signposting, is the most common complaint following autism assessment; with caregivers feeling abandoned after diagnosis and unsure of what health and education support they are entitled to (Crane et al., 2018; Hasson, 2019; Potter, 2017). These themes were identified almost twenty years ago in a study by Mansell and Morris (2004), which found that parents felt lacking in professional support and needed to seek support from community-led peer groups. A larger study by Crane et al. (2016) found that 61% of 1047 parents were dissatisfied with the level of support they received from services. This longstanding problem is acknowledged in the NHS Long Term Plan which outlines the need for improvement to autism services (NHS, 2019). However, many services are struggling to change pathways and support for children and families in the face of depleted resources. (Autistica, 2021).

1.2 Wakefield Children's Autism Assessment Pathway

1.2.1 Service Context

The Children's Autism Assessment Pathway in Wakefield provides multi-disciplinary assessments for children and young people (<18 years). Between October 2020 and September 2021, the service accepted 1072 referrals and 660 of these progressed to multidisciplinary assessments (Mid Yorkshire Hospitals NHS Trust, 2022).

1.2.2 Assessment

The multidisciplinary assessment process is consistent with national guidance (National Institute for Health and Care Excellence, 2017) and once concluded, all caregivers, regardless of the assessment outcome, are signposted to an optional online follow-up clinic to discuss the findings and/or further support.

1.2.2 Online Follow-Up Clinic

The follow-up clinic is facilitated on an opt-in basis and is delivered via NHS Attend Anywhere. Caregivers are signposted to the follow-up clinic during a telephone appointment to discuss the outcome of their child's autism assessment, and details of how to book an appointment are provided in the diagnostic report.

Follow-up clinics run on the first Monday of every month and are facilitated by an Assistant Psychologist and a Speech and Language Therapy Assistant. A representative from Wakefield Inclusion SEND Support Service (WISSENDSS) also attends to support caregivers in liaising with schools around their child's educational needs. There is no pre-determined structure to the follow-up clinic; it is caregiver-led, and support is tailored to the individual needs of their child. Caregivers receive a written summary following the clinic.

1.3 Service Evaluation Project (SEP)

1.3.1 Commissioning

This SEP was commissioned by Dr Emma Knowles, Principal Clinical Psychologist and Clinical Lead, in the Wakefield Children's Autism Assessment Pathway.

1.3.2 Rationale

Wakefield Children's Autism Assessment Pathway, in collaboration with local parent forums, identified post-diagnostic support to be an area of need in their service. In response to this need, and in line with national guidance (National Institute for Health and Care Excellence, 2017), the online follow-up clinic was introduced as part of the pathway. While initially well-attended, uptake has been lower than anticipated and this is the first opportunity to evaluate the follow-up clinic.

1.3.3 Aims

The aim of this SEP was to evaluate the acceptability of the follow-up clinic by exploring a) the experiences of caregivers who attended between March and September 2022, and b) the views of clinicians who facilitate and signpost to the follow-up clinic.

2. Method

2.1 Design

A mixed-methods design was employed to address the aims of the SEP (Timans et al., 2019). An online survey was used to explore caregivers' experiences of the follow-up clinic; the combination of quantitative and qualitative data allowed for multiple-

choice ratings and the exploration of individual responses. Semi-structured qualitative interviews were used to explore the views of clinicians' in the service.

It may have been preferable to also use semi-structured interviews with caregivers to explore their experiences in richer detail. However, prior service evaluation projects within the service had garnered low response rates from caregivers and so, in collaboration with the commissioners, it was decided that an anonymous online survey would increase the likelihood of caregivers responding to the SEP by placing the least demand on them at a potentially stressful time (shortly after their child's assessment). Follow-up clinics were held remotely and so it was anticipated that an anonymous online survey would be more accessible and also increase the likelihood of honest, critical feedback.

2.2 Ethical Approval

Ethical approval for this SEP was granted by University of Leeds School of Medicine Research Ethics Committee DClIn sub-REC: DClInREC 21-008 (Appendix A).

2.3 Recruitment

2.3.1 Caregiver Survey

Caregivers who attended the online follow-up clinic between March and September 2022 were invited to take part in this SEP at the end of their appointment. Facilitators of the follow up clinic talked through the Participant Information Sheet with caregivers, and this was also provided via email (Appendix B). As the follow-up clinic was held online, informed consent was obtained verbally, documented by the lead facilitator, and witnessed by the co-facilitator (Appendix C).

2.3.2 Clinician Interviews

A recruitment email, including a Participant Information Sheet (Appendix D), was sent to all clinicians within the autism assessment pathway. Clinicians were asked to reply to the email to express interest in taking part and a link to an online consent form was provided via email (Appendix E).

2.4 Data Collection

2.4.1 Caregiver Survey

A 10-item survey, combining multiple-choice and open-ended questions, was developed using Online Surveys (Appendix F), and a link was emailed to consenting caregivers. To increase accessibility, caregivers were offered the option of completing the survey as a semi-structured interview with the researcher over the phone, via video call, or in person. Interpreting services were available for caregivers for whom English was a second language.

2.4.2 Clinician Interviews

Consenting clinicians were contacted via email to arrange a convenient date/time for the interview. A six-item semi-structured interview schedule was developed (Appendix G). Interviews were conducted via Microsoft Teams, were recorded for transcription, and lasted approximately 20 minutes.

2.5 Data Analysis

2.5.1 Descriptive Statistics

Descriptive statistics were used to analyse demographic information and responses to multiple-choice survey questions.

2.5.2 Rapid Qualitative Analysis

Responses to open-ended survey questions and interview transcripts were analysed using Rapid Qualitative Analysis as outlined by (Hamilton, 2013) and shown pictorially in Figure 1. Thematic Analysis (Braun & Clarke, 2006) was considered as an alternative method of analysis; however, this can be extremely time consuming, which was disadvantageous for the purpose of this SEP. Rapid Qualitative Analysis has been found to deliver methodologically rigorous results in a timely manner (Taylor et al., 2018).

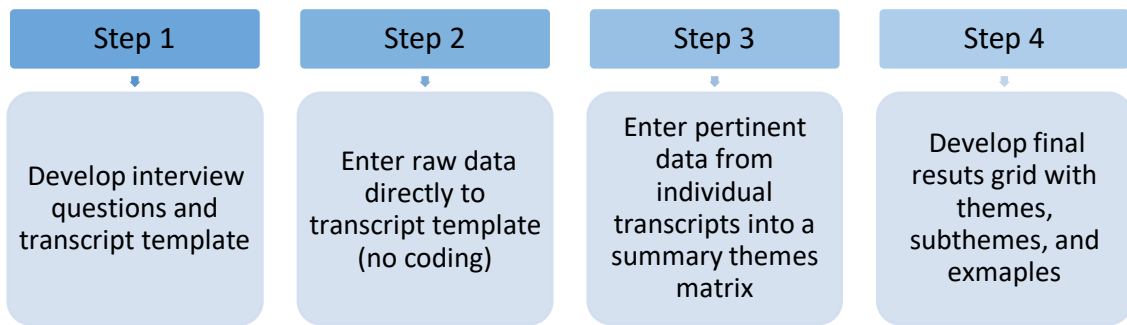


Figure 1. Process of Rapid Qualitative Analysis (Hamilton, 2013)

Credibility Checks

To support the reliability of themes and subthemes, credibility checks were carried out by a Clinical Psychologist in the commissioning service and two Trainee Clinical Psychologists who were independent to the project. Credibility checks were concordant with the original analysis and did not result in any changes.

3. Results

3.1. Caregiver Survey

3.1.1 Participants

Thirty-six follow-up clinic appointments were available between March and September 2022. Of the available appointments, 20 were attended by caregivers (56% of total capacity). 16 of the caregivers who attended the follow-up clinic consented to participate in the SEP. Of those who consented, 11 caregivers completed the survey (68.7% response rate). All caregivers opted to complete the online survey independently.

As shown in Figure 2, 100% of caregivers who completed the survey self-identified as female and White British. Two were aged between 25-34 years old, seven were aged between 35-44 years old, and two were aged between 45-54 years old.

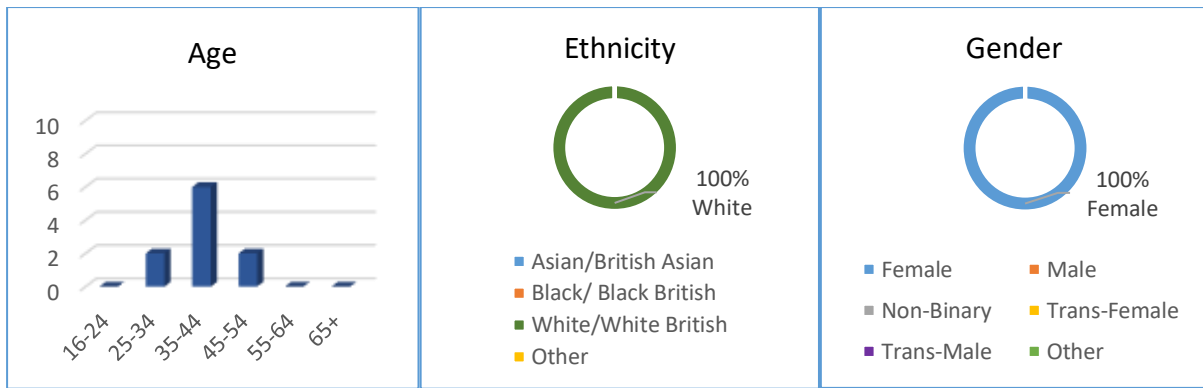


Figure 2. Demographics of caregivers who responded to the survey (n=11)

3.1.2 Survey Findings

Quantitative Data

As shown in Figure 3, nine caregivers rated the follow up clinic as ‘Helpful’ or ‘Very Helpful’, one rated as ‘Neither Helpful nor Unhelpful’ and one as ‘Unhelpful’.

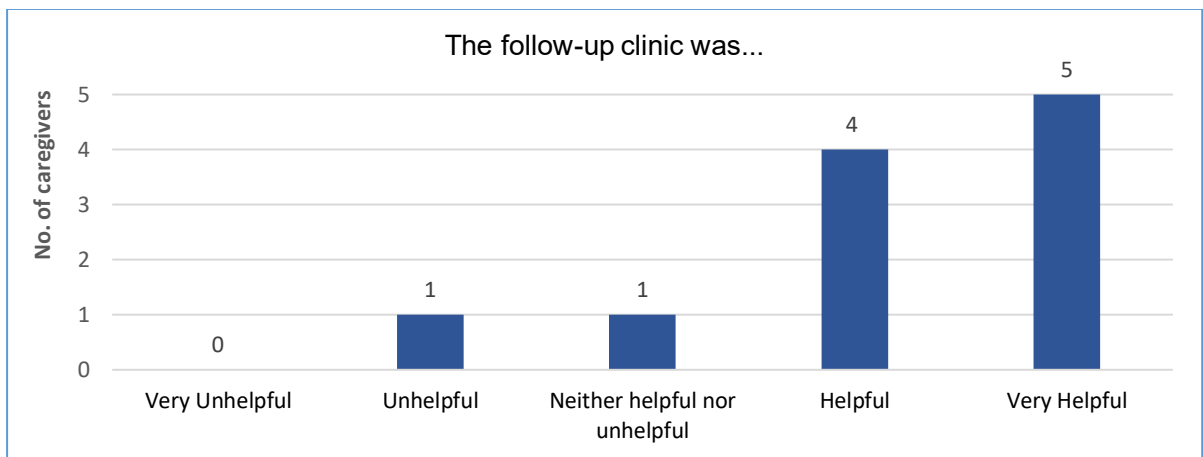


Figure 3. Caregiver ratings of how helpful/unhelpful they found the follow-up clinic

Ten caregivers reported that their questions were answered adequately by the facilitators, and that they were signposted to other sources of support. The remaining caregiver did not comment on what they felt was missing from their experience (Figure 4).

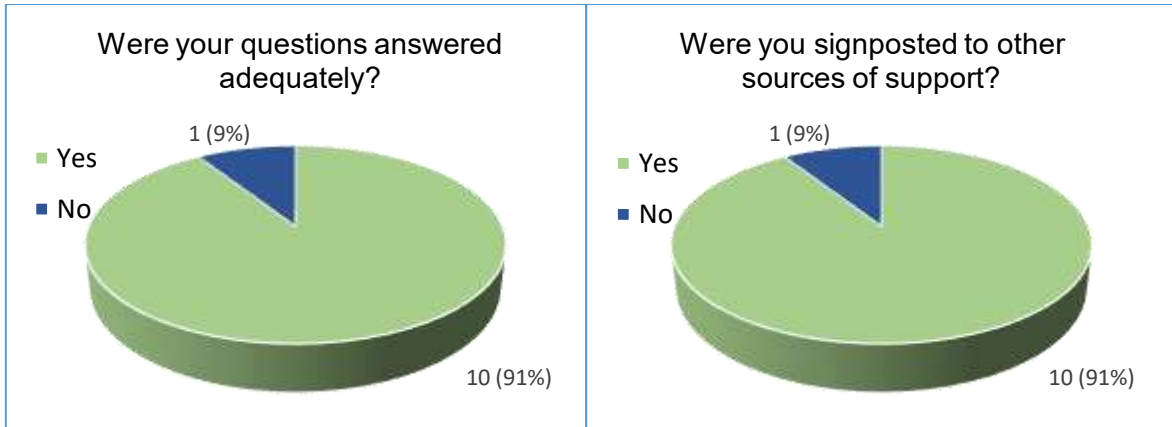


Figure 4. Caregiver responses to ‘Were your questions answered adequately?’ and ‘Were you signposted to other sources of support?’

Ten caregivers rated their overall experience of the follow up clinic as ‘Good’ or ‘Very Good’. One caregiver rated their experience as ‘Poor’ (Figure 5).

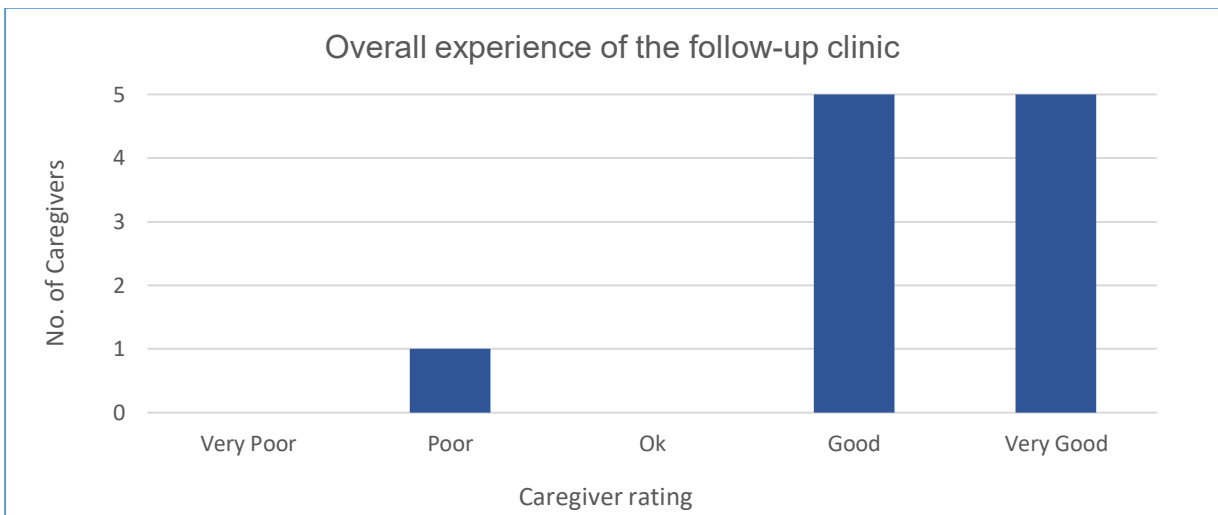


Figure 5. Caregiver ratings of their overall experience of the follow-up clinic.

Qualitative Data

Rapid Qualitative Analysis of responses to open-ended questions revealed three main themes: *Feeling Heard, Guidance and Support, and Facilitation Issues* (Appendix H). The themes and sub-themes are presented in Figure 6 and reported below.

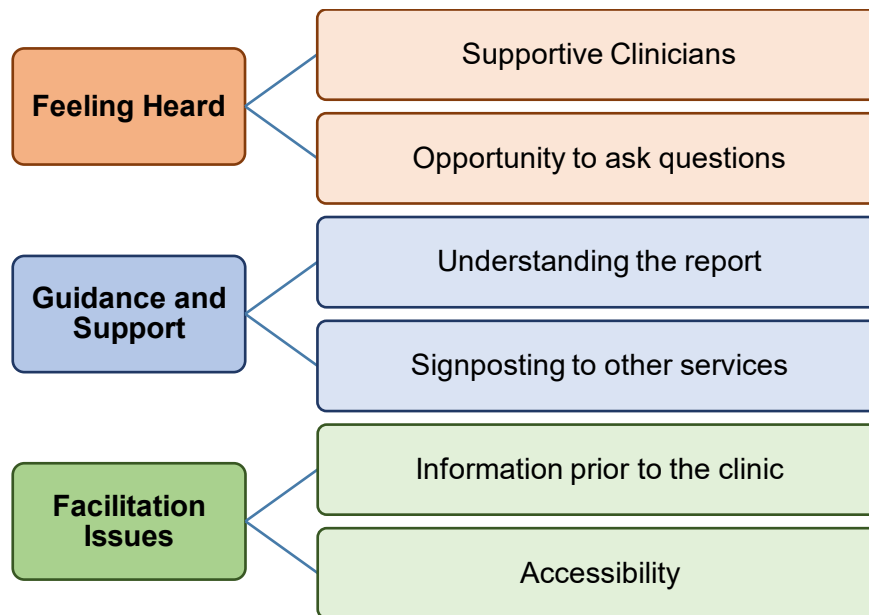


Figure 6. Themes and sub-themes from caregiver responses to open-ended survey questions

Theme 1: Feeling Heard

The first theme that emerged was *Feeling Heard*, and within this two sub-themes emerged: *Supportive Clinicians* and *Opportunity to ask Questions*.

Sub-theme 1a: Supportive Clinicians

Caregivers reported feeling listened to and supported by the facilitators of the follow-up clinic: *“Everyone listened – they were very helpful and supportive of me”* (Participant (P) 1). Others found it helpful to *“talk things through with [clinician]”* (P7) and felt: *“...reassured that we are doing what we can to support our child”* (P4).

Caregivers valued speaking with professionals from a range of backgrounds: *“It was good that there were people with different areas of expertise”* (P1), and with professionals who were not involved in their child’s autism assessment: *“It was helpful having separate input from different personnel”* (P6).

Sub-theme 1b: Opportunity to ask questions

The majority of caregivers valued the space to ask questions following the assessment: *“Our experience was positive, there were loads of opportunities to ask questions that I had forgotten about during assessment”* (P1) and *“I really appreciated*

the opportunity to talk about my concerns” (P2). While one caregiver commented that: *“Some [questions were answered] and some weren’t”* (P8).

Theme 2: Guidance and Support

The second theme that emerged was *Guidance and Support*, and within this two subthemes emerged: *Understanding the report* and *Signposting to other services*.

Sub-theme 2a. Understanding the report

The opportunity to discuss their child’s diagnostic report was among the reasons for caregivers attending the follow-up clinic, with one caregiver stating that they wanted to: *“Understand the report more”* (P11). Another caregiver was satisfied with the facilitators’ responses to questions and stated that *“they explained parts of the report well”* (P3).

Subtheme 2b: Signposting to other services

Seeking further support was also among the main reasons for caregivers attending the follow-up clinic: *“[I attended] for more information on what support is available”* (P8). The majority of caregivers reported that they had been signposted to other services and support in the local area and indicated this was helpful: *“they gave me information on different places and groups of support and advice”* (P1), *“They gave good advice on what to mention to school”* (P3), and they valued the written summary following the clinic: *“I had an email within the day with useful links”* (P2).

Theme 3: Facilitation Issues

The third theme that emerged was that of *Facilitation Issues*, and within this two subthemes emerged: *Information prior to the clinic* and *Accessibility*.

Sub-theme 3a: Information prior to the clinic

Caregivers were uncertain about the purpose of the follow-up clinic, and elements of the appointment took them by surprise: *“I didn’t expect as many people to be there”* (P5). Caregivers suggested that they would have benefited from more information ahead of the follow-up clinic: *“It would have been helpful to have more information about what the appointment entailed and what it was about”* (P10).

Subtheme 3b: Accessibility

Caregivers commented on the length of time between the assessment and accessing the follow-up clinic: *“My only criticism is the length of time between assessment and receiving information”* (P4).

With reference to the follow-up clinic being facilitated online, caregivers commented on the limited functionality of NHS Attend Anywhere: *“The chat function should work both ways, it would have been helpful if I could type a message”* (P5). Some caregivers expressed a preference for an appointment in person: *“It would have been better face to face”* (P6).

3.2 Clinician Interviews

3.2.1 Participants

Six clinicians provided informed consent and completed interviews. As shown in Figure 7, 100% of clinicians who were interviewed self-identified as female and White British. Five were aged between 25-34 years old, and one was aged between 35-44 years old. The sample of clinicians included one Assistant Psychologist, one Clinical Psychologist, one Speech and Language Therapy Assistant, and three Speech and Language Therapists. All clinicians either facilitated or signposted to the follow-up clinic as part of their role.

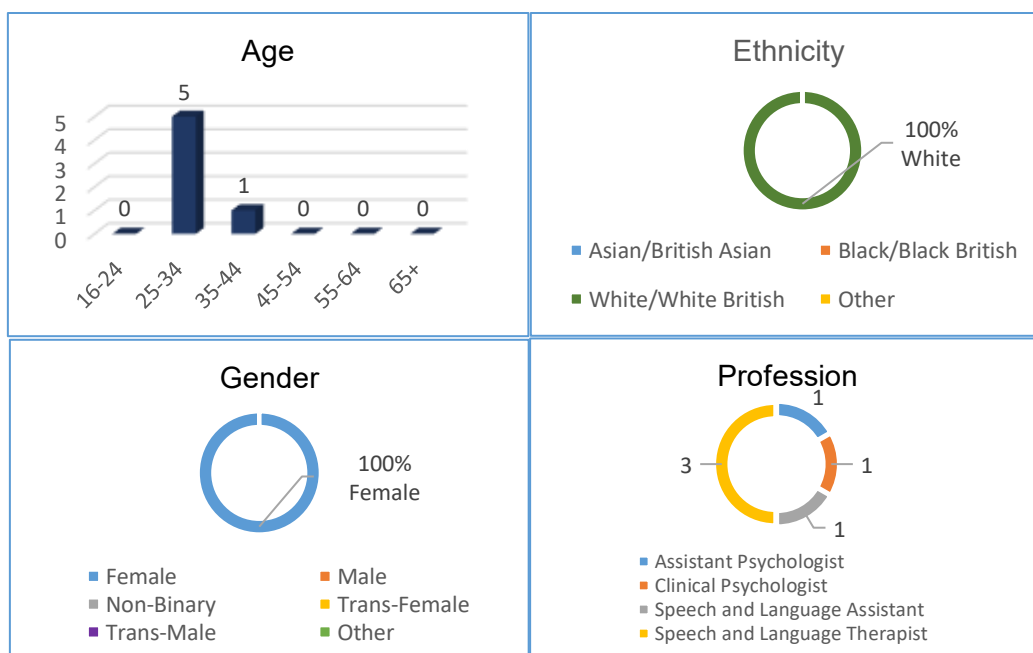


Figure 7. Demographics of clinicians who participated in interviews (n=6)

3.2.2 Interview Findings

Rapid Qualitative Analysis of interview transcripts revealed three main themes: *Valued Resource*, *Facilitation Issues*, and *Awareness* (Appendix I). Themes and sub-themes are presented in Figure 8 and reported below.

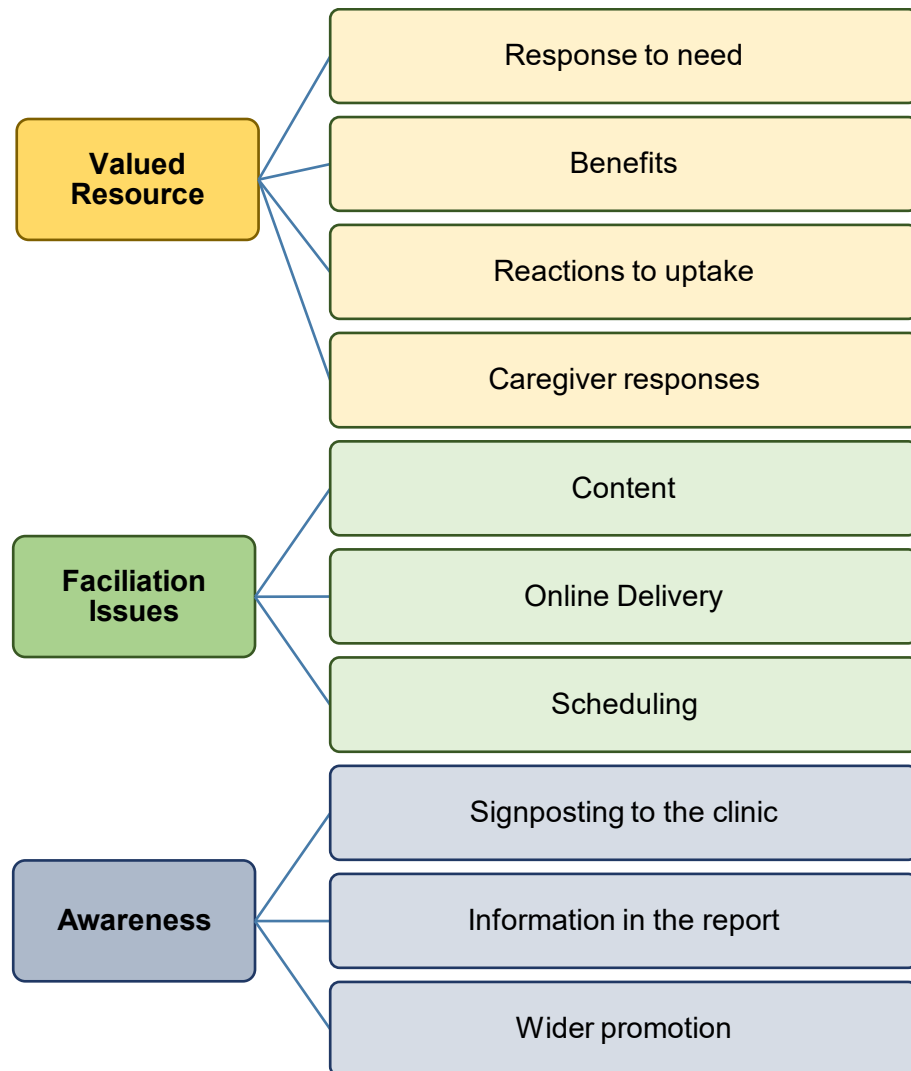


Figure 8. Themes and sub-themes from clinician interviews.

Theme 1: Valued Resource

The first theme that emerged was that the follow-up clinic is a *Valued Resource* and within this, four sub-themes emerged: *Response to need*, *Benefits*, *Reactions to Uptake* and *Caregiver Responses*.

Sub-theme 1a: Response to need

Clinicians reflected on the national lack of post-diagnostic support, and on their position in providing the service: *It's obviously in the NICE guidelines, but I think we're quite unique in offering it* (P6). Collaboration with local parent forums in developing the follow-up clinic was also a focus: *We went to parent forums and one of the things that they didn't like is that when the autism assessment was finished, they felt that nothing else happened... the general consensus was that they wanted something after they had a chance to read the report* (P4).

Sub-theme 1b: Benefits

The majority of clinicians viewed the follow-up clinic positively: *I think it's really great that we offer it - I talk about it to everybody on the feedback* (P3). Clinicians also reflected on the benefits of offering the clinic to all families who have been through the assessment process, regardless of diagnostic outcome: *It's a good port of call for those parents who don't know a lot about autism and have just got this really overwhelming diagnosis. I think it is also really good for those ones where it's not the outcome they expected* (P1). They also commented upon the follow-up clinic functioning as an important final step in the assessment pathway: *It's really valuable because it's their last opportunity to access more information* (P2) and an opportunity for educational support before discharge: *WISENDSS are the link between parents and schools...they are amazing... such an asset to the follow-up clinics* (P5).

Sub-theme 1c: Reactions to Uptake

The majority of clinicians shared that they were surprised and confused that so few caregivers have accessed the clinic: *I think all of us are really surprised that it hasn't been more taken up, particularly because it came from the parent forums* (P4). There was a drive to increase uptake to the clinic and provide effective post-diagnostic support to families: *I think it's about trying to, like, work out ways to improve accessibility for parents to make sure that everyone's getting the support they need* (P5).

Sub-theme 1d: Caregiver responses¹

Clinicians discussed caregiver responses to the follow up clinic from their experiences of signposting and facilitating. At the point of signposting, caregivers' responses are

¹ Participant numbers are not included in this section as this could make quotes identifiable.

described as enthusiastic: *“From my experience they’re really kind of happy to hear that there is another opportunity to come back with questions; they’re generally quite enthusiastic”*. However, at the point of attending the follow up clinic, responses are varied: *“Some are a little bit confused or overwhelmed, and a bit unsure of what to bring. They haven’t had enough information beforehand – they can get agitated”*.

Theme 2: Facilitation Issues

The second theme that emerged was *Facilitation Issues*, and within this three subthemes emerged: *Content*, *Online Delivery* and *Scheduling*.

Sub-theme 2a: Content

Clinicians reflected on the content of the follow up clinic and shared their suggestions on how this could be improved. Some suggested that the follow-up clinic could be more targeted at specific areas of need: *“It would be absolutely brilliant if we were able to offer targeted sessions as well, like on sleep or behaviour - sort of providing materials... talking through things”* (P4). Others highlighted the need to provide separate post-diagnostic support for children and young people: *“I do think we should look at what we can give the child or young person as well”* (P3).

Sub-theme 2b: Online Delivery

All clinicians referred to the online delivery of the follow up clinic. Some commented on the potential flexibility: *“It’s probably convenient for people who can’t travel into the hospital. And I suppose that opens it out so that wider family members can attend as well”* (P1). The majority of clinicians commented on the online delivery as a potential barrier to caregivers attending the clinic: *“I do wonder whether the fact it is just over video... if it feels less credible for parents”* (P3) and whether it may create inequalities in terms of access: *“I wonder in terms of like digital poverty – they might not have access a laptop or iPad or smartphone or know how to use it”* (P6). There was a consensus in the data that the option of a face-to-face appointment would be beneficial: *“I think if we offered the option of face to face that would help get better attendance - you can have a better, more well-rounded discussion”* (P4)

Sub-theme 2c: Scheduling

Clinicians wondered whether the current schedule might limit the uptake to the clinic: *“They’re only doing them on Mondays, so I don’t know if that would have an impact on*

people's availability if it's, like, their working hours" (P1) and whether offering more flexible appointments might help: "Maybe it needs to be a bit more flexible in terms of time - it might be a lot more accessible for parents to have a later time slot - so maybe that kind of 5-6pm slot, or even a Saturday" (P2).

Clinicians also discussed that some caregivers may require additional support to access the follow up clinic and made suggestions on how these might be met: *"Maybe we need to be checking they have access to the digital devices that they need and asking if they need any support in booking on to the clinic...there might be a language barrier...letting them know there can be an interpreter if needed" (P6)*

Theme 3: Awareness

The third theme that emerged was *Awareness* and within this, three subthemes emerged: *Signposting to the clinic*, *Information in the report*, and *Wider promotion*.

Sub-theme 3a. Signposting to the clinic

Clinicians wondered whether uptake to the follow-up clinic could be influenced by the ways in which caregivers are signposted to it: *"Maybe it's the wording when we talk about it, you know, 'if you've got any questions about the report'...perhaps they think they don't need to book" (P3)* and whether there may be inconsistencies in how it is presented among clinicians: *"With so many different clinicians, I do wonder whether there is variation in how much it's emphasised in feedback calls" (P6)*. They also suggested that caregivers may not be aware of the link to third sector input: *"I don't know whether they know that it could help them in terms of school support" (P5)*. Some suggested that it would be helpful to ensure consistency in the information given to caregivers: *"Maybe a more scripted introduction of how the clinicians emphasise the follow up clinic in the feedback" (P6)*.

Sub-theme 3b: Information in the report

The majority of clinicians thought that information about the follow-up clinic within the diagnostic report is unclear: *"It's written right at the bottom of the report and the report's like, 13 to 17 pages long. It doesn't really like lend itself to being a priority" (P3)* and there was a focus on needing to review how this information is provided: *"It really needs to be moved to the front page and highlighted or in bold, and just a bit more information about it generally and what to expect" (P3)*.

Sub-theme 3c: Wider promotion

Clinicians discussed the need to increase the presence of the follow-up clinic through wider promotion. It was suggested that providing accessible literature, separate to the diagnostic report, would be helpful in raising awareness: *“Making sure parents and families are signposted to the website... and having leaflets that are accessible for families, so making sure they’re printed off in different languages”* (P6). It was also suggested that caregivers could be given information about the follow-up clinic earlier in the assessment process: *“If it was entrenched in everything that the families got from the beginning of the assessment, it would just become a part of the pathway... rather than it being tagged on at the end”* (P6).

4. Discussion

The aim of this SEP was to evaluate the online follow-up clinic within Wakefield Children’s’ Autism Assessment Pathway by exploring caregivers’ experiences and clinicians’ views; both are explored in turn below.

4.1 Caregivers’ experiences

Responses to the survey suggest that the main reasons for caregivers attending the follow up clinic was to seek further support and to understand the outcome of their child’s autism assessment. This is consistent with current evidence, which suggests these are the key areas in which caregivers require support (Crane et al., 2018). The majority of caregivers felt the follow-up clinic was a valued space to ask questions following their child’s assessment and that their questions were answered satisfactorily, which suggests the follow up clinic is working to mitigate the risk of caregivers feeling abandoned after diagnosis (Galpin et al., 2018). They also valued the signposting to local sources of support such as caregiver forums and third sector organisations, which is an encouraging contrast to studies which have highlighted dissatisfaction with signposting (Crane et al., 2016) but could potentially reflect a longstanding issue whereby families rely on peer support in the face of limited service provision (Mansell & Morris, 2004). A recent review by (Legg & Tickle, 2019) found that in addition to informational support, caregivers value emotional support around

adjustment following their child's autism diagnosis. It is therefore encouraging that caregivers in this SEP were very positive about their interactions with the facilitators of the follow up clinic, and reported feeling listened to and supported.

While the majority of caregivers responded positively, one caregiver, whose child had not received an autism diagnosis, rated their experience as 'poor' and did not feel that signposting was adequate. While these ratings could potentially reflect dissatisfaction with the outcome of the assessment, it may also suggest that the follow-up clinic is currently less helpful for caregivers of children who have not received a diagnosis, and it may be helpful to review the support for this group.

Online delivery of the follow-up clinic appeared to be acceptable for most caregivers, which endorses recent evidence that suggests online education and support is effective for caregivers of autistic children (Roberts et al., 2019). However, some caregivers did express a preference for face-to-face contact and it is important to note that by nature, these SEP findings do not reflect the views of caregivers whose attendance may have been impeded by the online delivery (Barrantes, 2007).

The main area of improvement from caregiver responses was the need for more information prior to the clinic. Caregivers were unsure of what to expect and, as they are required to opt-in, it is important to consider the potential impact of uncertainty on the uptake of the follow-up clinic. Caregivers were not fully aware that the follow-up clinic is a step towards further support for their child; given the identified need for post-diagnostic support (Crane et al., 2016), making this explicit in signposting information may support uptake to the clinic.

While these findings indicate that there are some challenges to caregivers accessing the clinic, it is encouraging that the content is largely meeting the needs of caregivers who attend particularly at a time of limited resources in the NHS (Autistica, 2021; NHS, 2019). It is important to note that caregivers were asked to participate in the survey by the facilitators of the clinic, who they felt supported by. There is the potential for this to create a response bias (Elston, 2021), by which caregivers are reluctant to provide critical feedback. However, this risk was mediated by the survey being completed independently and anonymously.

It is important to note the demographics of the caregivers in this SEP. All caregivers self-identified as White British, and while this is a relatively small sample, it could

potentially reflect inequalities in access to support for caregivers from minoritized ethnic backgrounds. Health inequalities for people from minoritized backgrounds are well-documented across the NHS (Patel & Hanif, 2022), and so it is vital that services evaluate their processes in line with anti-racist practice (West Yorkshire Health and Care Partnership, 2022) to ensure equity of access to required support.

4.2 Clinicians' views

Interview findings indicate that clinicians view the follow-up clinic as a valuable resource. There was emphasis on the importance of providing post-diagnostic support in line with NICE guidance (National Institute for Health and Care Excellence, 2017). Clinicians were aware of national dearth of post-diagnostic support for families (Hasson, 2019) and were surprised by the limited uptake to their follow-up clinic, particularly as it was implemented in response to local need. Clinicians were focused on improving uptake to the clinic and ensuring that all caregivers and their children receive the support they need.

Clinicians' views supported the preference for face-to-face clinics expressed by some caregivers. Clinicians wondered whether the online platform may impede access to support for some caregivers, which is a valid concern within the context of digital poverty (Barrantes, 2007); many people may not have access to devices to attend appointments online. The increase in virtual appointments during the COVID-19 pandemic revealed 'a new digital dimension to inequality...and risks further disadvantaging those already being left behind' (Seah, 2020). Therefore, suggestions by both caregivers and clinicians to offer the option of a face-to-face follow-up clinic seems pertinent in improving access. Clinicians also wondered whether the current scheduling of the clinic during working hours would make it difficult for working caregivers to access. It may not be feasible for caregivers to take leave from work to attend an optional appointment. This is particularly salient during the current cost of living crisis, with recent reports suggesting that families are less able to attend appointments due to financial difficulties (Iacobucci, 2022).

There was a consensus among clinicians that the information currently provided before the clinic is unclear and potentially inconsistent, which supports the feelings of uncertainty reported by caregivers. Insufficient information may also explain the

disparity between caregivers' enthusiasm when first signposted to the clinic and their confusion when they attend. Lack of clear and individualised post-diagnostic information and signposting for families of autistic children has been highlighted (Potter, 2017) and this has been shown to compromise the delivery of care in health settings (Ratna, 2019). There was a strong focus on redressing this issue in the clinician data by developing clear and detailed information for caregivers, and consistency in how this is introduced.

Clinicians also reflected upon potential developments in the post-diagnostic support provided. Suggestions included more targeted psychoeducation sessions for caregivers and separate support for children following their assessment, which is associated with improved outcomes for children and their families (Dawson-Squibb et al., 2019; Gordon et al., 2015; Leadbitter et al., 2022; Legg & Tickle, 2019; Potter, 2017). This is also consistent with current priorities outlined by Autistica (2021), based on evidence that effective psychoeducation following diagnosis is vital in challenging stigma for children and supporting caregivers' well-being (Papadopoulos et al., 2019).

4.4 Strengths and Limitations

A strength of this SEP was that the researcher was independent to the commissioning service and therefore potential biases were reduced. Another strength lies in the design of data collection; the survey format increased the likelihood of honest and critical feedback, support to participate was available to caregivers if needed, and the SEP includes the views of both clinicians and caregivers.

In terms of limitations, the sample size for the caregiver survey was relatively small. This partly reflects the limited uptake to the follow-up clinic; however, these findings still only represent 55% of caregivers who attended the follow-up clinic during the timeframe of the SEP. Clinician interviews yielded comparatively more data than the caregiver survey, which potentially risks privileging the clinician perspective in the narrative of the SEP and subsequent recommendations. However, attempts were made to mitigate this risk by addressing caregiver and clinician data separately and ensuring that both perspectives were reflected in the recommendations. Views on the accessibility of the clinic are limited to those caregivers who attended; future research may focus on the views of those who have not opted in. The demographics of

participants may indicate a limitation in the generalisability of the findings; the sample was entirely female and White British. This could suggest inequalities in accessing support for families from minoritized ethnic backgrounds, which provides an important focus for further research.

4.7 Conclusion and Recommendations

The findings of this SEP suggest that the follow-up clinic is valued by clinicians and largely meets the needs of caregivers who attend. Clinicians and caregivers highlighted some challenges with the accessibility of the clinic, which underpin the following recommendations:

Signposting to the follow-up clinic

The service may wish to consider:

1. [Introducing the follow-up clinic to caregivers at the beginning of the assessment process](#), to ensure they are aware of post-diagnostic support as part of the pathway.
2. Developing a shared checklist of information to share with caregivers to ensure [consistent signposting](#). This may include emphasising that a representative from WISENDSS will be present to provide advice around education.
3. Producing [literature to promote the follow-up clinic](#) within the pathway, e.g., a leaflet outlining the purpose of the clinic, what to expect, and details of how it can be accessed.
4. Asking caregivers whether they are interested in attending the follow-up clinic at assessment feedback and [passing details to facilitators to make contact and discuss any support needed to attend](#), once the report has been disseminated.
5. [Highlighting information about the follow-up clinic in the diagnostic report](#) to ensure this acts as an effective reminder for caregivers.

Delivering the clinic

The service may wish to consider:

1. Offering the option of [face-to-face appointments with flexible timings](#) according to individual need.
2. Reviewing [support for caregivers of children who did not receive an autism diagnosis](#).
3. Providing [targeted psychoeducation sessions](#) in addition to the current Q&A structure.
4. Providing separate post-diagnostic [support for children and young people](#).

Equity of access

The service may wish to consider:

1. Comparing the demographics of caregivers in this SEP with the population they work with to [investigate whether there are inequalities in accessing support for caregivers from minoritized backgrounds](#).
2. Ensuring literature about the follow up clinic is available in [different languages](#)
3. Ensuring caregivers are aware that [interpreting services](#) are readily available if required.

4.9 Dissemination

The findings of the SEP will be disseminated in the following ways:

1. A report will be shared with the commissioning service
2. Poster presentation at the University of Leeds SEP Conference
3. Presentation at the Wakefield Autism Assessment Pathway team meeting

5. References

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6. Appendices

Appendix A – Ethical approval

From: Anita Dorsett [REDACTED]
Sent: 17 February 2022 09:58
To: Leanne Rogan [REDACTED]
Cc: Gary Latchford [REDACTED]
Subject: DClin sub-REC approval

Dear Leanne,

I am pleased to let you know that your application **Parent/Care Giver Experiences of an Online Post-diagnostic Follow up Clinic in a Child Autism Assessment Pathway**, reference number **DClinREC 21-008**, has been approved by the DClin sub-REC. You may commence with your data collection when you are ready.

This is conditional on you making no more than one call a week for four weeks or four calls in total to attempt to contact video/phone call participants. If the phone calls are unsuccessful a follow up email may then be sent as outlined in your application. If you need to make any changes to the approved proposal, please briefly outline the changes and rationale in an email to Gary and me wait for approval before implementing the change.

Best wishes,

Anita Dorsett

From: Anita Dorsett [REDACTED]
Sent: 12 August 2022 10:59
To: Leanne Rogan [REDACTED]
Cc: Gary Latchford [REDACTED]
Subject: RE: SEP ethics REVIEW

Hi Leanne,

I am happy to approve this amendment on behalf of the DClinREC on the condition that you remove one sentence from the participant information sheet and return a copy of the revised information sheet to me for filing. (The sentence to remove is the one with my second comment against it. The first comment is editorial only.) Once you have sent me the revised sheet you may go ahead with the amendment (without needing to hear from me again). Good luck - I hope this new plan gives you the participants you need.

Best wishes,

Anita

Anita Dorsett

Research Coordinator, Doctoral Programme in Clinical Psychology, University of Leeds. **Usual workdays are Thursdays and Fridays. Leeds DClinPsychol Extranet site:**
<https://dclinpsych.leeds.ac.uk/>

Participant Information Sheet

Service Evaluation Project: Caregiver/caregiver experiences of an opt-in online follow up clinic in the children’s autism assessment pathway.

You are being invited to complete a survey as a part of a service evaluation project. Before you decide it is important for you to understand why this is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You can ask the autism assessment team or contact the researcher (Leanne Rogan - contact details at the end of this document).

What is the purpose of the project?

We aim to gather feedback on caregiver/caregiver experiences of the follow up clinic in the children’s autism assessment pathway to help us understand what is helpful for families and highlight areas for improvement. We will be asking for feedback via an online survey (or via telephone/video call, if you prefer) from caregivers/caregivers who attend the follow up clinic between February and September 2022.

Why have I been chosen?

We are inviting all caregivers/caregivers who have attended the follow up clinic in the children’s autism assessment pathway to give feedback on their experience. You have been invited to take part as you attended the follow up clinic following your child’s assessment.

Do I have to take part?

It is up to you to decide whether or not to take part. It is entirely voluntary.

If you do decide to take part, you will be given this information sheet to keep. The clinicians from the autism assessment service who shared this information with you will confirm your consent to take part verbally. A record of verbal consent will be made by the clinicians running the follow up clinic and this will be stored securely within the service, separate from any clinical records to protect your confidentiality. Record of consent will never be linked with information collected in the survey.

You can withdraw (without giving a reason) at any time up until the point your survey responses are submitted. Once your survey responses are submitted it will not be possible to withdraw as your data is completely anonymous and it would not be possible to track your responses to remove them from the database.

What do I have to do?

If you choose to take part, we will ask you to complete a brief survey which will ask questions about your experience of the follow up clinic. You will only need to complete the survey once.

You can choose to complete the survey:

Online (you will receive a link via email). This should take 5-10 minutes to complete.

or

Via the telephone/video call with Leanne Rogan (researcher). In this case, the autism assessment service will share your first name and preferred contact method to enable her to contact you and complete the survey with you. This should take 10-15 minutes to complete.

What are the possible disadvantages and risks of taking part?

The survey will require approximately 10 minutes of your time to complete. No obvious risks have been identified. However, if you feel you require support, the following organisations may be helpful:

Wakefield Early Support Advice Information and Liaison Service

(WESAIL): 01924 304 152

Wakefield Inclusion Special Educational Needs & Disabilities Support Service (WISENDSS): 01924 302471.

You can also contact the research team (contact details below) if you have any queries or concerns about taking part in this study.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those who complete the survey, it is hoped that this work will help to improve the follow up clinic for families who access it in the future.

What will happen to my personal information?

A record of your verbal consent to take part will be kept securely within the service – this will include your name only and will be stored separately from your child's clinical records and will not be linked to the survey data.

Any contact information that we collect to enable you to complete the survey (e.g., telephone number, email address and first name) will be kept securely, will be strictly confidential and will not be linked in any way to the responses to the survey. If you choose to complete the survey with the researcher, this information will be shared with them via secure nhs.net email and will be permanently deleted once research has been completed. Aside from that stated above, the researcher will not have access to your personal/identifiable information or any information relating to your child's assessment or clinical records.

We will not collect any identifiable information in the survey. All survey responses will be completely anonymous and will be stored in a secure and encrypted folder to allow the researcher to analyse the data. The data will be kept strictly confidential and only those involved directly in the service evaluation will have access to it. If you provide any information in your responses which could be potentially identifiable, this will be removed to protect your confidentiality.

All information will be stored in line with NHS Information Governance.

What will happen to the results of the research project?

Anonymous data will be analysed by the researcher and findings will be shared with the children's autism assessment team to inform any potential changes/improvements to how the follow up clinic is run in the future. Findings may also be shared with other autism teams in Mid Yorks Trust to inform how services are run in the future.

The researcher will also produce a 5000-word assessed report and presentation as part of their Doctoral Training. This report may include direct quotes from survey responses, but these will not be identifiable. While there is no intention at present, there is a possibility that this report may lead to publication. The publication would not include any identifiable information.

What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

We collect information about your age, ethnicity, and disability status. This will help us to understand who is currently attending the follow up clinic. We will ask you questions about your experience of the follow up clinic, including what was helpful or unhelpful. This information will help us to make changes and improve the service moving forward.

Who is organising/ funding the research?

This service evaluation is commissioned by the Mid Yorks Children's Autism Assessment Pathway at Pinderfields Hospital, Wakefield, and is being completed by Leanne Rogan, Psychologist in Clinical Training at the University of Leeds, as part of Doctoral Training Coursework.

Ethical approval for this project has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds; DCLinREC 21-008.

Contact for further information

Researcher:

Leanne Rogan, Psychologist in Clinical Training
Doctorate in Clinical Psychology Training Programme
Leeds Institute of Health Science, Worsley Building
University of Leeds
Leeds, LS2 9NL

Email: [REDACTED]

Supervisor:

Dr Gary Latchford, Joint Programme Director
Doctorate in Clinical Psychology Training Programme
Leeds Institute of Health Science, Worsley Building

University of Leeds

Leeds, LS2 9NL

Tel: [REDACTED] email [REDACTED]

Thank you for taking the time to read through this information. A copy of this information sheet will be provided to all caregivers/caregivers who have been offered the opportunity to take part.

Appendix C – Caregiver Consent Form

RECORD OF VERBAL CONSENT

Title of Project: Caregiver experiences of an online post-diagnostic follow up clinic in a children's autism assessment pathway. **Researcher:** Leanne Rogan, Psychologist in Clinical Training

1. I confirm that information about the study (PISv1) has been explained to me and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that participation is voluntary, and I am free to withdraw (without giving a reason and without my medical care/legal rights being affected) at any time up **until** I have submitted by survey responses. I understand that I cannot withdraw my responses after this point as they are anonymous and cannot be traced back to me.

3. I understand that my anonymous responses will be stored securely for the purpose of this service evaluation and direct quotes may be included in the service evaluation report. Anonymous data will be stored securely for up to 3 years in line with NHS Information Governance.

4. I agree to take part in this study.

5. I agree for the survey link/PISv1 to be emailed to me using the address I have provided and for my email address to be stored securely for a maximum of 8 weeks from this date.

6. I agree to my first name and telephone number/email address to be shared with the researcher for the purpose of contacting me to complete the survey via telephone/video call. These will be stored securely for a maximum of 8 weeks from this date.

Name of Participant

Date

Name of Person
taking verbal consent

Date

Signature

Name of Person
witness to verbal consent

Date

Signature

Appendix D – Clinician Information Sheet

Participant Information Sheet: Clinician interviews

Service Evaluation Project: Caregivers' experience and clinicians' views of an opt-in online follow up clinic in the children's autism assessment pathway.

You are being invited to take part in a brief interview as part of a service evaluation project. Before you decide it is important for you to understand why this is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You can ask the autism assessment team or contact the researcher (Leanne Rogan - contact details at the end of this document).

What is the purpose of the project?

We aim to gather feedback on caregiver/caregiver experiences of the follow up clinic in the children's autism assessment pathway to help us understand what is helpful for families and highlight areas for improvement. We will be asking for feedback via an online survey from caregivers/caregivers who attend the follow up clinic between February and September 2022.

In addition, we aim to gather clinicians' views on the online follow up clinic, including potential facilitators/barriers to caregivers accessing the clinic and suggested improvements.

Why have I been chosen?

You have been invited to take part in this service evaluation project as you are a clinician who works in the children's autism assessment pathway, and you are involved with the follow up clinic through either a) providing information about the clinic to caregivers at the assessment feedback appointment or b) facilitating the online follow up clinic with caregivers.

Do I have to take part?

It is up to you to decide whether or not to take part. It is entirely voluntary.

If you do decide to take part you will be invited to complete an online consent form (a link will be emailed to your nhs.net email account). The consent form will collect basic demographic information about you (name, contact details, age, ethnicity etc.) and will include key points of the service evaluation for you to consent to. Once you have confirmed your consent, an interview will be arranged at a time that is convenient for you.

You can withdraw (without giving a reason) at any time before or during the interview. Once the interview has taken place, you can withdraw your data up to 7 days after the date of the interview. After this point, the data will have been anonymised and transcribed for analysis.

Interview data will be anonymised, stored securely, and separately to demographic information collected during the consent process.

What do I have to do?

If you choose to take part, you will be asked to take part in a brief interview with the researcher, which should last no longer than 20 minutes. Interviews will be held online using MS Teams and will be audio recorded for the purpose of transcription and analysis.

What are the possible disadvantages and risks of taking part?

The interview will require approximately 20 minutes of your time to complete. No obvious risks have been identified. However, you can contact the research team (contact details below) if you have any queries or concerns about taking part in this study.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those who complete the survey, it is hoped that this work will help to improve the follow up clinic for families who access it in the future.

What will happen to my personal information?

A record of your consent will be stored securely on the researcher's secure Online Surveys account. Only the researcher can access this information. Your name and contact details will be used to arrange and facilitate the interview – all correspondence will take place using nhs.net to nhs.net email accounts.

All information will be kept securely, will be strictly confidential and will not be linked in any way to interview data. All interview data will be transcribed, anonymised and will be stored in a secure and encrypted folder to allow the researcher to analyse the data. The data will be kept strictly confidential and only the researcher will have access to it. If you provide any information in your responses which could be potentially identifiable, this will be removed to protect your confidentiality.

All information will be stored in line with NHS Information Governance.

What will happen to the results of the research project?

Anonymous data will be analysed by the researcher and findings will be shared with the children's autism assessment team to inform any potential changes/improvements to how the follow up clinic is run in the future. Findings may also be shared with other autism teams in Mid Yorks Trust to inform how services are run in the future.

The researcher will also produce a 5000-word assessed report and presentation as part of their Doctoral Training. This report may include direct quotes from survey responses, but these will not be identifiable. While there is no intention at present, there is a possibility that this report may lead to publication. The publication would not include any identifiable information.

What type of information will be sought from me and why is the collection of this information relevant for achieving the research project’s objectives?

Information about your age, ethnicity and job role will be collected to help us understand the demographics of clinicians involved with the online follow up clinic. You will also be asked questions about your experience of talking to caregivers about the follow up clinic, your views on the follow up clinic, your thoughts on potential facilitators/barriers to caregivers accessing the follow up clinic and if you have any suggestions to improve the follow up clinic. This information will help us to make changes and improve the service moving forward.

Who is organising/ funding the research?

This service evaluation is commissioned by the Mid Yorks Children’s Autism Assessment Pathway at Pinderfields Hospital, Wakefield, and is being completed by Leanne Rogan, Psychologist in Clinical Training at the University of Leeds, as part of Doctoral Training Coursework.

Ethical approval for this project has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds; DClinREC 21-00 (17/2/2022; amendments approved: 12/8/2022)

Contact for further information

Researcher:

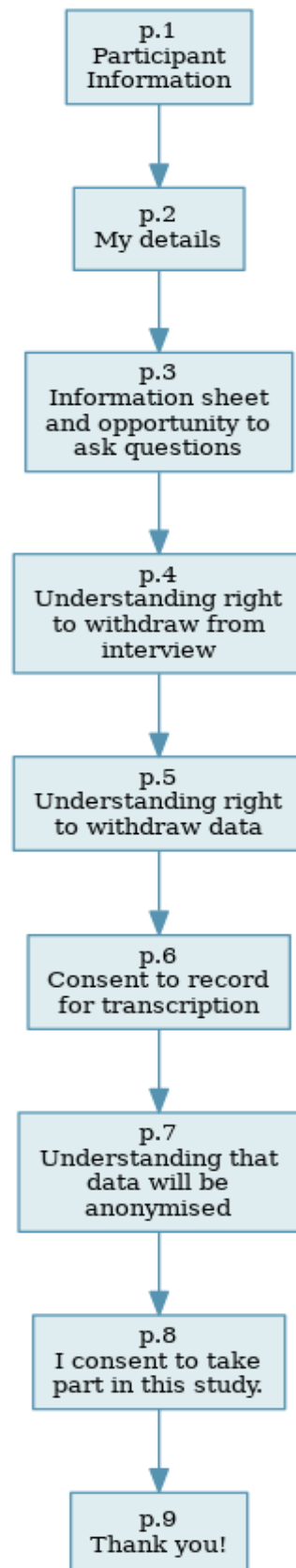
Leanne Rogan, Psychologist in Clinical Training
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Email: [redacted]@leeds.ac.uk

Supervisor:

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Doctorate in Clinical Psychology Training Programme
Leeds Institute of Health Science, Worsley Building
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Tel: [redacted] /email: [redacted]

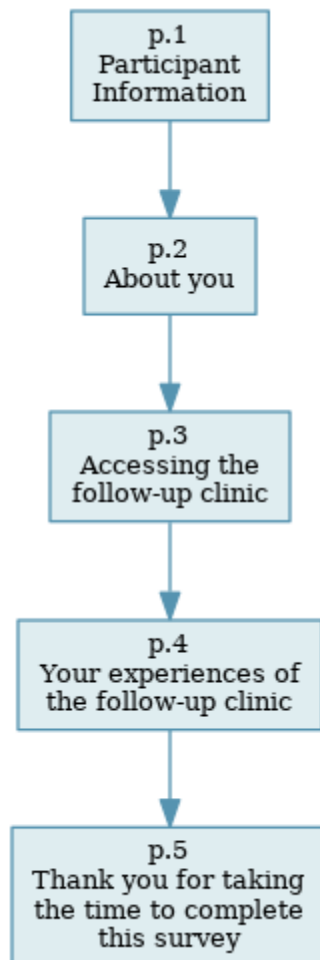
Thank you for taking the time to read through this information. A copy of this information sheet will be provided to all clinicians who have been offered the opportunity.

Appendix E – Clinician Consent Form (Map)



Appendix F – Caregiver Survey Map

Evaluation of the online follow up clinic in the children's autism pathway



Appendix G – Clinician Interview Schedule

Domain	Question
Usual practice	1. Can you tell me about your experience of the follow up clinic as part of the autism assessment pathway?
	2. Referrers: How do you introduce the follow up clinic to families? In your opinion, how is it generally received by parents? Facilitators: How do you facilitate the follow up clinic? In your opinion, how do families respond to the follow up clinic?
Clinician Attitudes	3. a. How do you view the follow up clinic? b. How do you think it is viewed within the pathway?
Facilitators and Barriers	4. Do you think there are factors that make it more likely for caregivers to attend the clinic?
	5. Do you think there are any barriers to caregivers accessing the clinic?
Innovation	6. a. Are there ways that you think the follow up clinic could be improved? b. Are there ways that you think <i>access</i> to the follow up clinic could be improved?
Other observations	

Appendix H – Caregiver Survey Theme

Summary Matrix	Survey	Example Quotes (n=11)
Theme 1: Feeling Heard		
Opportunity to ask questions	1, 2, 5, 8, 10	<ul style="list-style-type: none"> • <i>Our experience was positive, there were loads of opportunities to ask questions that I had forgotten about during assessment” (1)</i> • <i>“I really appreciated the opportunity to talk about my concerns” (2)</i> • <i>“Some [of my questions were answered] and some weren’t” (8)</i>
Supportive Clinicians Reassurance Range of expertise	1, 2, 3, 4, 5, 6	<ul style="list-style-type: none"> • <i>“I felt reassured that we are doing what we can to support our child” (4)</i> • <i>“Everyone listened – they were very helpful and supportive of me” (1, 3)</i> • <i>“It was good that there were people with different areas of expertise ” (5)</i> • <i>“It was helpful having separate input from different personnel” (2, 6)</i>
Theme 2: Guidance and Support		
Signposting to other services <ul style="list-style-type: none"> • Educational support Signposting to services/resources	1, 2, 3, 8, 9	<ul style="list-style-type: none"> • <i>“[I attended the clinic] for more information on what support is available” (8)</i> • <i>“[I attended the clinic] to understand the report more” (9)</i> • <i>“They gave good advice on what to mention to school” (3)</i> • <i>“I was given information on different support groups and service available” (1, 3)</i> • <i>“I had an email within the day with useful links” (2)</i>
Understanding the report	1, 2, 3, 6, 11	<ul style="list-style-type: none"> • <i>“They explained parts of my child’s report well” (3)</i> • <i>Reasons for attending: “to understand the report more” (11)</i>
Theme 3: Facilitation Issues		
Information about the clinic <ul style="list-style-type: none"> • Lack of information about the clinic • Uncertainty 	1, 2, 3, 8, 9, 10	<ul style="list-style-type: none"> • <i>“It would be helpful to have more information about what the appointment entailed and what it is about” (10)</i> • <i>“I wasn’t expecting as many people” (5)</i> • <i>“It wasn’t what I expected” (8)</i>
Accessibility <ul style="list-style-type: none"> • Online vs face to face • Online functionality • Time between assessment and report 	1, 4, 5, 6, 11	<ul style="list-style-type: none"> • <i>“The chat function should work both ways, it would have been helpful if I could type a message” (5)</i> • <i>“It was a slow process” (11)</i> • <i>“My only criticism is the length of time between assessment and receiving written information (4)</i> • <i>“It would feel more supportive if there were two follow-up appointments” (1)</i> • <i>“It would have been better face to face” (6)</i>

Appendix I – Clinician Interview Themes

Themes	Subthemes	Examples Quotes(n=6)
Valued Resource	Response to need <ul style="list-style-type: none"> In line with NICE guidance Response to need raised by parent forums Not every service offers follow-up 	<p><i>“It’s obviously in the NICE guidelines, but I think we’re quite unique in offering it” (P6)</i></p> <p><i>“We went to parent forums and were asking parents to talk about their experiences and one of the things that they didn’t like is that when the autism assessment was finished, they felt that nothing else has happened... We explored with parents and the general consensus was that they wanted something after they had chance to read the report” (P4)</i></p>
	Benefits <ul style="list-style-type: none"> Good port of call for all families, regardless of outcome ‘Last chance’ to get support from the team Linking in with third sector education support 	<p><i>“I think it’s really great that we offer it - I talk about it to everybody on the feedback.” (P3).</i></p> <p><i>“It’s a good port of call for those parents who don’t know a lot about autism and have just got this really overwhelming diagnosis. I think it is also really good for those ones where it’s not the outcome they expected” (P1)</i></p> <p><i>“It’s really valuable because it’s their last opportunity to access more information” (P2)</i></p> <p><i>“WISENDSS are the link between parents and schools...they are amazing... such an asset to the follow up clinics” (P5).</i></p>
	Reactions to Uptake <ul style="list-style-type: none"> Surprised and confused by limited uptake Identified need for change to increase uptake 	<p><i>“I think all of us are really surprised that it hasn’t been more taken up and particular because it came from the parent forums” (P4).</i></p> <p><i>“I think it’s about trying to like work out ways to improve accessibility for parents to make sure that everyone’s getting the support they need” (P5).</i></p>
	Caregiver Response <ul style="list-style-type: none"> Enthusiasm/Confusion - not sure what to bring Difference between response at signposting and during the clinic 	<p><i>“From my experience they’re really kind of happy to hear that there is another opportunity to come back with questions; they’re generally quite enthusiastic”.</i></p> <p><i>“Some families like the flexibility and the chance to take the lead with their questions, but some are a little bit confused or overwhelmed, and a bit unsure of what to bring. They haven’t had enough information beforehand – they can get agitated”.</i></p>

Facilitation Issues	Content <ul style="list-style-type: none"> • Potential for targeted sessions in addition to Q&A appointment • Longer-term provision that caregivers can book onto at any point after assessment/discharge when problems arise. • Not currently offering specific support for the child/young person - do they know they can join too? Can we run groups/1:1 for them? 	<p><i>"It would be absolutely brilliant if we were able to offer targeted sessions as well, like on sleep or behaviour - sort of providing materials... talking through things" (P4).</i></p> <p><i>"If we had bit of a Q&A, but there was also maybe some like a focused sessions on certain areas that they could book onto that could be quite good. Like sessions and support around like sleep for example" (3)</i></p> <p><i>"In an ideal world perhaps, it would more of a clinic that can be accessed post-assessment as needed - I think families would certainly find it useful to be able to access that sort of six months down the line when they're encountering some questions and some problems.</i></p> <p><i>"I do think we should look at what we can give the child or young person as well, and not just the parent. Like if we could run groups or 1:1 slot, because I feel that we're not really giving anything to the child after they have that diagnosis" (1)</i></p>
	Online Delivery <ul style="list-style-type: none"> • Online may be convenient for some people • Online might be a barrier – digital poverty, computer literacy, impersonal 	<p><i>"It's probably convenient for people who can't travel into the hospital. And I suppose that opens it out so that wider family members can attend as well" (P1).</i></p> <p><i>"I do wonder whether the fact it is just over video... if it feels less credible for parents" (P3)</i></p> <p><i>"I wonder in terms of like digital poverty – they might not have access a laptop or iPad or smartphone or know how to use it" (P6)</i></p> <p><i>"I think if we offered the option of face to face that would help get better attendance - you can have a better, more well-rounded discussion" (P4)</i></p>
	Scheduling <ul style="list-style-type: none"> • Only offered one day per month, on a Monday • During working hours – caregivers may not able to take time off 	<p><i>"They're only doing them on Mondays, so I don't know if that would have an impact on people's availability if it's, like, their working hours" (P1)</i></p> <p><i>"Maybe it needs to be a bit more flexible in terms of time - it might be a lot more accessible for parents to have a later time slot - so maybe that kind of 5-6pm slot, or even a Saturday" (P2).</i></p> <p><i>"Maybe we need to be checking they have access to the digital devices that they need and asking if they need any support in booking on to the clinic...there might be a language barrier, thinking about ... if parents feel able and confident. Letting them know there can be an interpreter if needed" (P6)</i></p>

Awareness	Signposting to the clinic <ul style="list-style-type: none"> • Could be variation in how the follow-up is introduced to caregivers at feedback – lots of different clinicians • Wording used when introducing the clinic, e.g., ‘if you have questions’ – potentially makes caregivers think it’s not for them • Maybe we could have script that all clinicians use to introduce the clinic to make sure everyone is getting the same information 	<p><i>“Maybe it’s the wording when we talk about it, you know, ‘if you’ve got any questions about the report’...perhaps they think they don’t need to book” (P3)</i></p> <p><i>“With so many different clinicians, I do wonder whether there is variation in how much it’s emphasized in feedback calls” (P6).</i></p> <p><i>“I don’t know whether they know that it could help them in terms of school support” (P5)</i></p> <p><i>“Maybe a more scripted introduction of how the clinicians emphasise the follow up clinic in the feedback” (P6).</i></p>
	Information in the Report <ul style="list-style-type: none"> • Information given to caregivers about the clinic is not clear • Written at the bottom of a very long report – gets lost. Move to the front page? • More information about what to expect, who will be there etc. 	<p><i>“It’s written right at the bottom of the report and the report’s like, 13 to 17 pages long. It doesn’t really like lend itself to being a priority” (P3)</i></p> <p><i>“It really needs to be moved from the bottom of the report to the front page and highlighted or in bold, and just a bit more information about it generally and what to expect” (P3).</i></p>
	Wider Promotion <ul style="list-style-type: none"> • Separate written information about the clinic could be made available to caregivers from the beginning • Signposting to the info on website/ develop Leaflets • Info available in different languages and caregivers know they can have an interpreter in the clinic if needed. 	<p><i>“Making sure parents and families are signposted to the website... and having leaflets that are accessible for families, so making sure they’re printed off in different languages” (P6).</i></p> <p><i>“If it was entrenched in everything that the families got from the beginning of the assessment, it would just become a part of the pathway...they would have that knowledge right from the beginning, rather than it being tagged on at the end” (P6).</i></p>