

An Evaluation of Parents' and Carers' Experiences of the
Calderdale Neurodevelopmental Assessment Pathway for
Children and Young People

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Introduction

Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition affecting one's ability to interact with the world, reflected by differences in social communication and restricted or repetitive behaviour (American Psychiatric Association, 2013). Research suggests that approximately 70% of individuals with ASD also meet criteria for other mental or behavioural conditions such as *Attention Deficit Hyperactivity Disorder*, or ADHD (Simonoff et al., 2008), characterised by persistent patterns of inattention, and/or hyperactivity and impulsivity (e.g. excessive physical movement or speech, or difficulties turn-taking) (American Psychiatric Association, 2013).

Whilst the two often frequently co-occur (Leitner, 2014), UK assessments have typically taken place under separate pathways. However, with increasing service pressure, the NHS Long Term Plan aimed to establish the most effective means of service delivery (NHS England, 2019). In this context, Male et al. (2020) reported that parents found separate pathways to be frustrating, often with duplication of assessment. In line with a recent report from Embracing Complexity (2019), the authors suggested that an integrated neurodevelopmental service model may make better use of limited resources and offer a more accurate understanding of children's needs.

Understanding the parent and carer perspective is key, as their testimonies form a vital part of diagnostic decision-making. In a synthesis of qualitative research into the same, Legg and Tickle (2019) highlighted three key parental needs. Firstly, they discussed parents' *informational* needs, and the importance of sufficient information being shared initially to clarify parents' expectations of the process. Post-diagnosis, knowledge about ASD was cited as being somewhat responsible for increased acceptance, adaptation and self-efficacy for some parents, underlining the importance of meeting parents' informational needs. In related findings from Crane et al. (2019), some parents reported a lack of clarity around the whole process and "how it all fits together", as well as having unclear expectations around the (lack of) post-diagnostic support. After receiving the diagnosis, parents reported feeling "directionless", wanting more information about "where you can get help". Secondly, Legg and Tickle (2019) proposed that parents' *emotional* needs are important throughout; it was important for parents concerns to be validated, given that guilt and self-blame is common.

Thirdly, the *relational* needs of parents were also highlighted. This included the need to feel listened to from the outset, and for clinicians to work to reduce power imbalances, with parents' own expertise being taken seriously. Indeed, other research found that whilst professionals acknowledged the importance of building a relationship with parents, some expressed caution and a sense of having to limit the amount of time parents spent "going into their stories" (Crane et al., 2018). Relatedly, several studies have reported parental disappointment with practitioners regarding the comprehensiveness of their assessment (Legg & Tickle, 2019). Similar findings were presented by Crane et al. (2018), with parents describing professionals' tendencies to focus on 'negatives'; this related to a sense of blame and failure in parents and lack of trust in professionals.

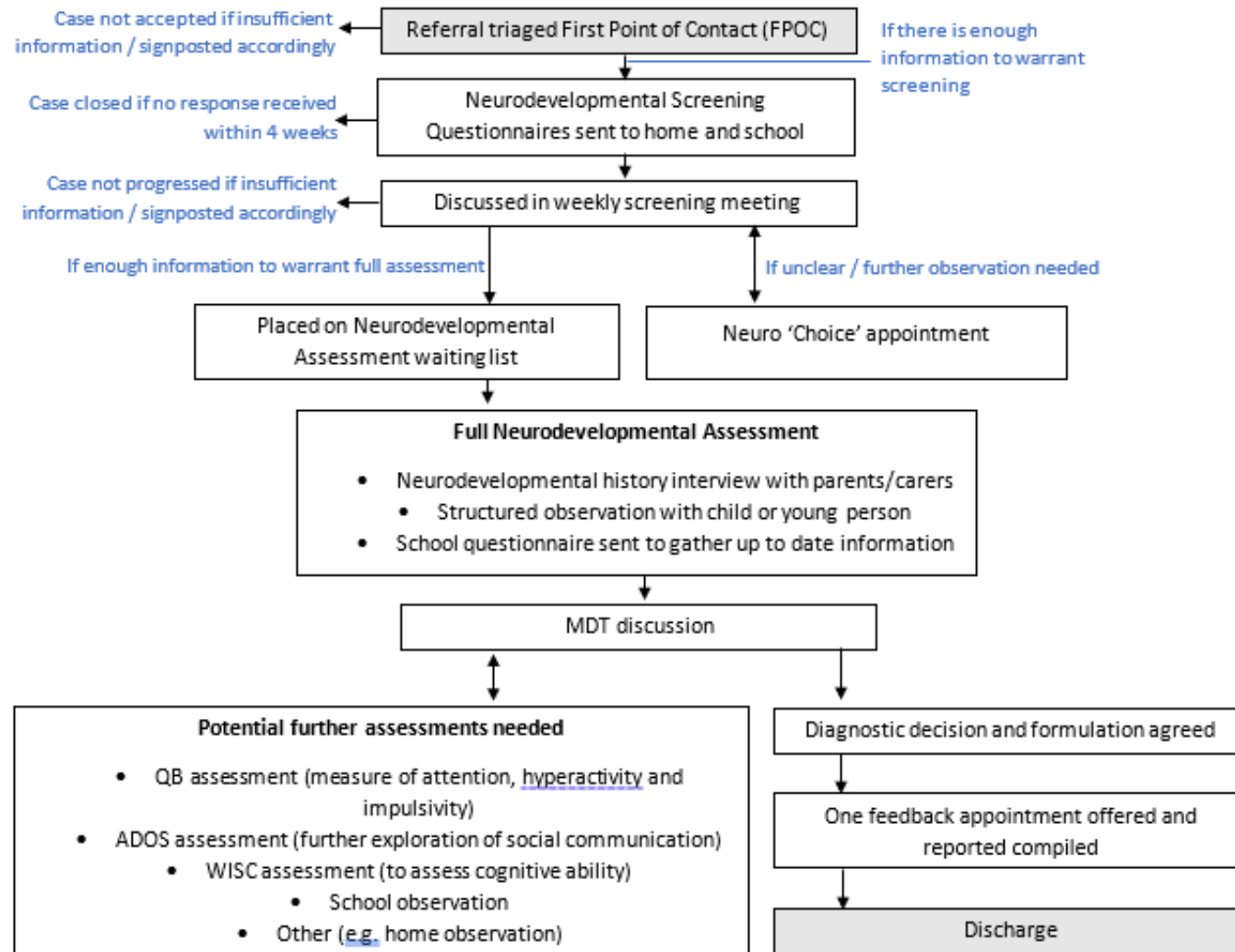
However, it should be noted that the quality of studies included in the review paper was variable, with over-reliance on some studies more than others. Additionally, both of the above studies included little contextual information about participants; it has been well documented that people of colour are particularly disadvantaged in the field of neurodevelopmental assessment and diagnosis (Begeer et al., 2009), thus it is unclear whether the findings represent this. It should also be noted that the review focused on ASD pathways only; equivalent research into ADHD pathways is lacking, as is the case for integrated assessment pathways. Nevertheless, whilst the above findings are limited in this way, given the relatedness of the two conditions, it may be argued that parental experiences of the diagnostic processes could be similar.

Service Context

Providing assessments for children and young people up to 18 years, the Neurodevelopmental Assessment Team sits within the Calderdale Open Minds Partnership, under the South West Yorkshire Partnership NHS Foundation Trust (SWYFT). The team is multi-disciplinary, consisting of representation from Clinical Psychology, Speech and Language Therapy and Psychiatry, as well as Mental Health Practitioners and support staff. In recent years, the decision was made to restructure the service and merge the previously separate assessment pathways in line with the above guidance. Figure 1 illustrates the combined pathway, correct at the time of writing.

Figure 1

Calderdale Neurodevelopmental Assessment Pathway



Aims

The aim of this project is to understand the experience of parents and carers who have supported their child through the combined neurodevelopmental assessment pathway in order to establish strengths of the service and areas for improvement.

Commissioning

The project was commissioned by Dr Katie Gregson-Curtis, Clinical Psychologist and Clinical Lead. There were no financial drivers or incentives attached to the completion of the project.

Method

Epistemology

The paradigm of pragmatism has recently been adopted in socially-oriented studies, moving away from metaphysical debates surrounding knowledge and reality and maintaining that one must use the methodological approach that most effectively addresses the aim or research question in hand (Kaushik & Walsh, 2019). With its primary goal being to generate practical, applicable knowledge that can be utilised to make important differences in society (Maxcy, 2003), pragmatism lends itself well to service evaluation and the aims of the current project and is therefore the epistemological perspective underpinning the work.

Design

A qualitative methodology was employed to understand participants' views about the pathway. Through a pragmatist lens, this methodology was deemed to be most suited to meeting the aims of the project; given that the pathway was relatively newly developed, it was felt that this approach would allow the author more scope to understand participants' views in detail, where quantitative methods might be too limiting.

Materials

Semi-structured interviews were used, not only to allow space for individual expression, but also to allow for reciprocity between the interviewer and the interviewee (Galletta, 2013), creating space for follow-up questions to be asked (Polit & Beck, 2010). In line with the pragmatist position, this allowed the conversation to remain appropriately focused to elicit

data that would meet the project aim. Focus groups were considered as an alternative. However, there were concerns that some participants may feel less able to speak openly or voice dissent, and that interviews would be better placed to capture diversity in experiences where this existed.

The interview schedule (Appendix A) was developed following a brief from the commissioner. It was agreed that the current lack of post-diagnostic support would not be explored with participants, as this is a reflection of local funding constraints, rather than a decision of the service.

Participants

Opportunity sampling was employed with the aim of recruiting 6-10 participants. Prospective participants were parents or carers of children who had recently reached the end of assessment and were attending a feedback appointment. Here, clinicians verbally provided brief information about the project. If consenting, they were later contacted by myself to discuss further, prior to them receiving full details of the project (Appendix B) and completing an online consent form (Appendix C). It should be noted that this recruitment strategy was borne out of a revision of an initial strategy which did not meet data protection criteria.

Eight individuals initially consented to participate, three of whom did not attend the meeting. Consequently, the final sample consisted of five participants. Demographic information was limited in order to maintain confidentiality. All participants were either parents or step-parents, and all were of White ethnicity. All children had received a diagnosis of ASD only, and at interview, all participants had attended their feedback appointment within the last four weeks.

Procedure

1:1 interviews were conducted via Zoom, ranging from 30-60 minutes. Participants had been invited to switch their camera off, if preferable; some voiced that this increased their willingness to participate. The interviews were recorded and stored securely, with unique identifying numbers assigned to ensure anonymity.

Analysis

The recordings were analysed using rapid qualitative analysis. Hamilton (2013) proposed that a rapid approach may be required when there is a pragmatic need for qualitative data and the project is time-limited project, with a pressure for progress and less time to “critique, reflect and synthesise”. As a result, Hamilton’s (2013) analytic process was followed, as set out in Table 1.

Table 1

Rapid qualitative analytic process

Step	Description
1: Interview summary template	Initial creation of neutral ‘domain names’ corresponding to each interview question, leading to development of structured ‘summary template’ (Appendix D). Template then assessed for usability and relevance before being populated with key information from each interview.
2: Matrix	Summaries transferred into a matrix (Appendix E) in order to “streamline the process of noting simultaneously and systematically similarities, differences, and trends in responses across groups of informants” (Averill 2002, p. 856).
3: Identification of themes	‘Surface level’ themes and subthemes identified using a semantic approach, without making interpretations beyond actual content of data.
4: Final summary grid	Themes refined as necessary via the above step to form final summary grid (Appendix F).

Ethical Approval

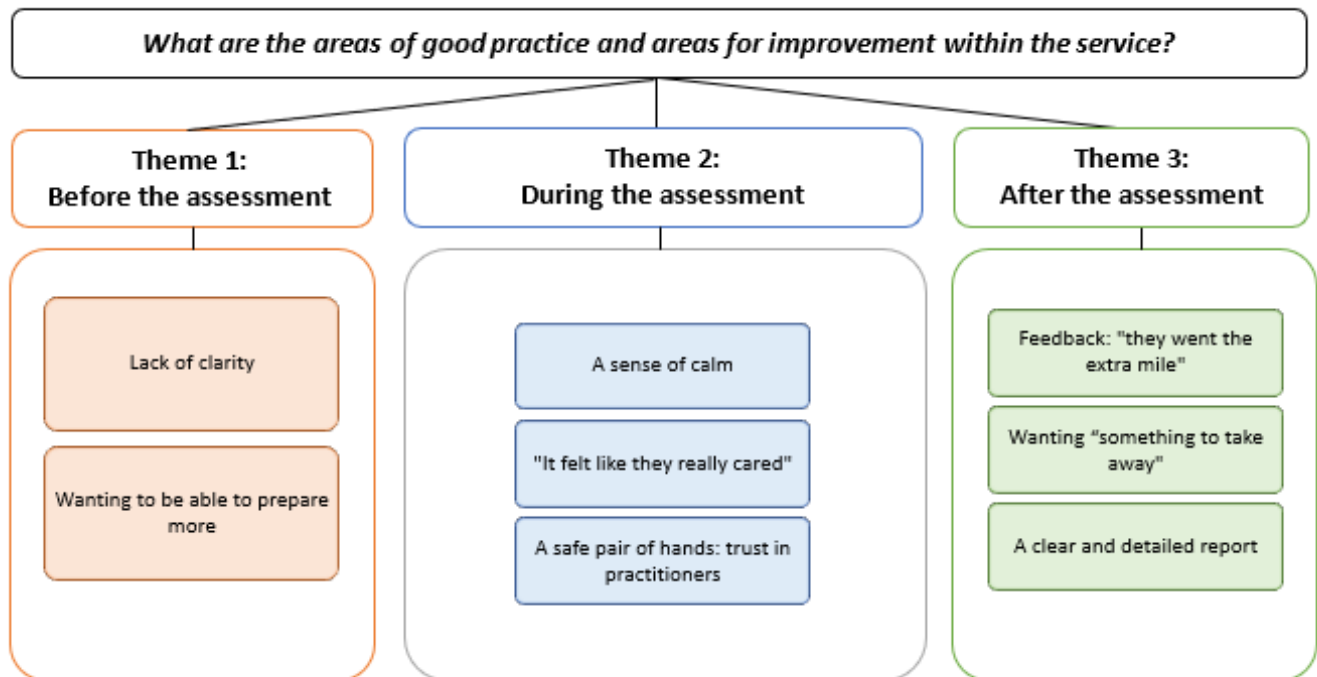
Ethical approval was granted by the DClInPsy Subcommittee of the School of Medicine Ethics Committee at the University of Leeds on 20th April 2022 (DClInREC 21-010). Additionally, the project was registered with the Trust’s Quality Improvement and Assurance Team on 24th February 2022 (registration number: 21/22SE45).

Results

Figure 2 illustrates the themes and subthemes identified through the analysis. The themes mirrored the initial overarching interview domains, as it was deemed that this would be the most appropriate way to clearly meet the project aims. As for the sub-themes, some mapped directly onto the initial interview sub-domains, whilst other sub-themes were apparent across multiple sub-domains.

Figure 2

Thematic map



Theme 1: Before the Assessment

Lack of Clarity

All participants felt that the letter inviting themselves and their child to the assessment did not provide clear enough information on what this would entail:

P2: It wasn't clear that the child would be in one room and parents in another.

P5: It's important - there's a lot resting on this meeting but I didn't know really what it'd involve.

P1: I had to read it a few times... I wasn't 100%.

Specifically, one participant had wanted to know more about the average timescale, and another about what to expect in terms of potential additional assessments. Moreover, only one participant received photographs of the staff team beforehand which was "useful" (P1); two others felt that this would have been beneficial.

Additionally, one participant talked about a lack of clarity with regards to who the letter referred to. They reflected on the wording which “appears to be aimed at very young children”, feeling that it may not be appropriate for older children. They also commented on the letter being addressed only to parents:

P5: With Autism... [they] sometimes feel overlooked... and I just think a separate piece of paper, a letter, just something – it means the world to them.

Ultimately, not knowing what would be asked of them as parents was difficult:

P5: I was nervous - I didn't sleep the night before.

P1: I felt like I was being checked on.

To help mitigate this, most participants felt that they would have liked “as much information at the start as possible” (P2) to “make the people feel comfortable before they go.” (P1).

However, one participant did state that being given too much prior information could be unhelpful:

P4: If I'd have known, I would have probably sat and stressed about it.

Wanting to be Able to Prepare More

Some participants felt that they would have appreciated prompts to prepare, such as to read the child's red book or discuss early years with family members. They felt that this would have left them feeling less reliant on their memory alone:

P1: Looking through [the red book] reminded me of things – it can be hard to remember off the top of your head.

P2: I didn't realise there'd be so much delving into previous medical history...if we'd have realised, we probably could've been a bit more prepared than we were.

P4: There was nobody else to go into that meeting with me to say what [my child] was like in [their] early years, there is only me.

Theme 2: During the Assessment

A Sense of Calm

All participants felt that the set-up on the day worked well, speaking positively about the practicalities. Two participants used the word “calm” (P1 and P4) and two others described their overall experience of the day as “straightforward” (P2 and P5). Moreover, it was felt that the process was clearly explained:

P3: I felt so well-informed from that point.

However, one participant did comment that expected timescales for the next steps could have been communicated more clearly one the day:

P2: You’ve been on the waiting list that long, and you finally get to have the initial assessment and you think, woah, a couple of weeks...and we’ve got to the end of it. I know that timescale is totally unrealistic – now - but it’d have been nice to have had a... [something to] guide our expectations.

All participants felt that appointment logistics worked well on numerous levels, including punctuality, co-ordination of the two parallel appointments, and length of the appointment:

P2: All the appointments were bang on time...which is helpful when [child] is there - with the routine, I think...all the questions of ‘where am I going, how long am I going to be there, when am I going home?’

P1: It felt like they worked well as a team.

P4: I didn’t feel rushed.

P5: I left the room feelings as though I got my point across.

P1: Talking about [my child] with her there in the room – it’s not really appropriate...I don’t feel comfortable saying everything...So [for this appointment], it was very good how immediately they took us separately and that was perfect...it worked well.

“It Felt Like They Really Cared”

All participants felt that practitioners were caring and sincere in their interactions with them; there was a significant amount of data to support this sub-theme. It was particularly apparent that participants felt heard:

P1: My concerns were validated.

P1: They wanted to hear my views as a parent.

P3: Even the strange little things that you’d think wouldn’t matter, they listened to and noted...they didn’t make me feel like a neurotic mum!

Moreover, participants experienced practitioners as “kind” (P1), “thoughtful” (P3), and “understanding” (P4), and most parents commented on a warm and sincere interpersonal style:

P1: They were human...it felt like they were just with you...they were just smiley and open.

P5: She made us at ease.

P2: All the people we dealt with were all really friendly, really understanding... couldn’t have asked for better really.

A Safe Pair of Hands: Trust in Practitioners

All participants conveyed a sense of feeling trusting and contained by practitioners. Firstly, practitioners adopted a transparent and suitably directive approach to the parent interview and this helped participants to provide the necessary information:

P3: They did what they said they’d do and stuck to their word.

P3: They were clear on what they were needing, wanting, expecting, looking for.

P1: They let me go off when I needed to and then drew me back in.

One participant reported that practitioners asked clear, concrete questions which allowed for objective answers to be provided. Practitioners also made the conversation feel accessible:

P5: They re-phrased questions when I didn’t understand.

Moreover, all participants stated that practitioners conducted the assessment in a way that felt “thorough”. This reassured participants that their child’s needs would not be overlooked:

P1: Staff were perceptive.

P1: I was reassured that they’d contact me afterwards if we didn’t cover everything.

P5: It started the minute they said hello” – observations were made from the outset.

P5: Because they were instantly watching how she behaved, they picked up on it, and I liked that because I thought, well, I feel a bit at ease.

P1: It was clear that notes had been read prior.

Whilst it could be suggested that reading clinical notes beforehand may bias practitioners’ judgements, some participants commented that staff appeared to make a fair, honest and balanced assessment of their child, including when there were discrepancies between the school’s account of the child, and the parents’:

P3: They were open-minded.

P1: It felt like there were no preconceptions.

P1: She said to me, “can you tell me her strengths and her positives?”, so it was a nice way to finish it off...you forget the good things...sometimes it’s nice to say those as well.

Theme 3: After the Assessment

Feedback: “They Went The Extra Mile”

Four participants appreciated the amount of information shared with them in relation to the outcome. It was generally felt that observations were discussed in detail, and that practitioners were reassuring:

P3: There was space to expand on information...they put me at ease.

P5: They went through every point of it and explained absolutely everything as much as they could...for what funding allowed her, she could not have done any more.

Two participants also commented on being particularly appreciative of advice and suggestions for next steps that the family might take, and information about available sources of support:

P2: They took a lot of time to explain things...and she did give us information about where we could go and, different websites we could look at and organisations we could get in touch with later. It just felt like she went the extra mile...you think: 'well what now?', and to be told there's nothing forward now... But, like I say, she didn't just leave it at that...so that was really, really good.

However, one participant felt that naming this appointment 'feedback' did not reflect the significance of the appointment and the information being shared within it:

P5: It sounds so office-like - that's what office people say in emails...feedback usually means they want to know what's gone wrong!

P5: It's a big thing in a family's life to be told your child's autistic...it's a lot more important than the word 'feedback'.

Moreover, there was variation across participants in terms of whether or not their child accompanied them to the feedback appointment. One participant commented on feeling uncomfortable with their child being present and reflected on the idea that whilst "they weren't being critical, they were just explaining it", it may have felt like a "character assassination" (P4) from the child's perspective, given the level of detail shared. Meanwhile, another participant, whose child did not attend the appointment, shared concerns about how best to share the outcome with them.

In addition, the absence of funding for post-diagnostic support came as a shock to some participants who wished that they had been more aware of this from the outset:

P5: ...from CAMHS, there's nothing – and that surprised me. That did surprise me.

Wanting "Something to Take Away"

For several reasons, all participants felt that they would have appreciated some printed material to take home, given that in some cases, there was "quite a wait between being given

the diagnosis and receiving the report” (P2). For example, some participants found it difficult to absorb and process the information provided:

P5: I felt like I'd won the lottery - but it's in pesos.

P4: ...a booklet... or a leaflet...where it's all written down for you, so you've got it.

Because it can be a bit of a barrage of information, and then you leave or you're like me and you lose your little piece of paper where you've written it all down...

P5: To be able to have something instantly, because you feel useless... I go home and, yes, my daughter's autistic but now what do I do... But if I've got the writing in my hand and places I could go...

Additionally, some participants stated that a brief document to confirm diagnosis whilst waiting for the report would have been useful for various reasons:

P1: When they tell me the diagnosis...maybe they could do a one-page letter to say 'just to confirm your diagnosis is this...the detailed information will follow but it can take up to so many weeks'...I think it would be a really useful thing if they could do that.

P5: ...because school – they won't act until I get a letter...I got a letter yesterday telling me my daughter was on the spectrum – not the full report, but a letter. Now that could be handed out on the day, which I could then go to school with.

P4: There's some information you want to share, but you don't want to share absolutely everything.

A Clear and Detailed Report

Only three of the five participants had received the report at the time of interview. All three appreciated the clarity, understandability, and level of detail contained within it:

P1: It was easy to digest and read.

P2: It was user-friendly.

P3: ...things that even I, as a parent, hadn't picked up on.

P3: Specific phrases were expanded upon... terms parents might not understand.

P1: This is the first report I've ever had that's mentioned both our names...

Acknowledging people as people rather than just a number...a real positive.

However, one participant felt that the report was somewhat "repetitive" (P2) in places. Moreover, whilst two participants found the recommendations in the report "really helpful" (P2), another commented that they "mostly felt vague" (P1) and wondered about the potential for additional advice or suggestions that felt more tailored to their child. Two participants also stated that they would have preferred the diagnosis to be at the beginning rather than the end, though the narrative beforehand was appreciated.

Discussion

Summary of Results

Overall, participants spoke positively about the service. However, levels of satisfaction varied across the different stages of the process.

Before the assessment, prior explanation of the process was felt to be lacking. This linked with a parental sense of anxiety, and, in hindsight, a lack of perceived preparedness. The findings mirror those reported by Crane et al. (2018) and Legg and Tickle (2019), suggesting that a need for greater transparency at this stage is not uncommon in services. On the day of the assessment, recalling medical history and relevant chronology was particularly challenging for most parents. Accordingly, provision of clearer information prior may not only improve parent's experiences, but may also be of clinical utility, given that such information is a crucial part of the diagnostic decision (National Institute for Health and Care Excellence, 2021). However, given the significance of the assessment, it is likely that, for many parents, no amount of prior information would alleviate this understandable concern. For example, Legg and Tickle (2019) found that parents often entered the assessment having struggled to understand their child's behaviour which often precipitated guilt and self-blame. Moreover, current findings indicate

that too much information could have the potential to exacerbate parental worry – hence, it appears that a careful balance should be struck.

In contrast to the above, findings clearly indicate that, overall, participants felt calm and well-informed *during* the assessment - although communication regarding the next steps could have been clearer for some. This suggests that the logistics of the assessment sessions themselves had generally been well considered and that the possible shortcomings of the letter are not reflective of a lack of process in reality. From a practical perspective, parents particularly appreciated the opportunity to speak with the practitioner without their child being present, and that they could express what was important without feeling time-pressured.

Indeed, strong communication between professionals and parents has been associated with the experience of positive, containing relationships for parents and their concerns (Legg & Tickle, 2019). Overwhelmingly, participants perceived staff to be genuinely caring which resulted in them feeling heard and valued. This aligns with other findings suggesting that parents have a need to be taken seriously by practitioners, with expertise shared both ways (Crane et al., 2018; de Clercq & Peeters, 2007). Studies report that parents often express a cautiousness of clinician's power (Legg & Tickle, 2019), thus the current findings suggest that clinicians were working skilfully to minimise any felt imbalance.

Relatedly, parents clearly trusted that the assessment was honest, comprehensive and balanced, incorporating discussion about the child's strengths as well as difficulties. This has important clinical implications: the earlier the child's needs can be identified and understood, the more effective that supportive interventions, such as those implemented at school, are likely to be (Lord, 2000). This was a particular strength of the service, where findings elsewhere point often towards a lack of parental faith in practitioners' judgements (Legg & Tickle, 2019). Indeed, Crane et al. (2018) found that this related to a tendency from professionals to focus on the 'negatives', which activated a sense of self-blame for parents. Conversely, exploration of the child's strengths was found to be associated with various benefits, including increased self-esteem and confidence in parenting. Taken altogether, such findings may, to some extent, explain why the assessment surpassed many parents' expectations.

Similarly, *after* the assessment, the feedback appointment was also felt to be comprehensive. Parents received a thorough explanation of the outcome, leaving them feeling “at ease”. This is a particularly positive finding, given what is known about the influence of practitioners on parents’ ability to adjust to their child’s diagnosis (Legg & Tickle, 2019). However, the sharing of such in-depth information raised some important points for consideration. Firstly, it was queried whether or not the term ‘feedback’ adequately reflected the significance of the meeting, and secondly, the presence or absence of the child in this meeting was variable, with responses suggesting that this decision may benefit from more consideration with parents prior to the meeting.

As aforementioned, the lack of funding for post-diagnostic support was not explored with participants, *per se*. However, some parents were not aware of this until the end of the process. This aligns with findings from Crane et al. (2018), with one participant stating they would have felt happier having known “exactly what they can offer me and can’t offer me”. They reported that parents felt “directionless”, and this is mirrored in current findings, with parents having wanted physical resources to take home whilst awaiting the report. However, most participants attributed this to difficulty absorbing the information in the appointment, rather than any lack of explanation from practitioners on the day. Relatedly, though with some comments made to the structure and repetition of some elements, parents generally valued the detailed nature of the report. However, it was felt that recommendations could be more tailored. These are important findings, as being well-equipped with knowledge about ASD may be partly responsible for increased acceptance and self-efficacy for parents post-diagnosis (Legg & Tickle, 2019).

Reflexivity

Whilst no longer affiliated with the service, I previously worked with the team during clinical training. I enjoyed the placement and was able to form positive working relationships with colleagues. Elliott et al. (1999) commented on the importance of owning one’s perspective in qualitative study; from a pragmatic perspective, I know that this experience influenced my decision to choose this project, and it is possible that it shaped my interpretation of the data. However, I strived to be mindful of such potential bias throughout the analysis. My

interpretations were surface-level only, and engagement with the data was systematic; I frequently returned to the raw data to ensure I was reflecting participants' experiences and not my own assumptions. Moreover, themes were cross-cutting and grounded clearly in the data (Hamilton, 2013). Credibility checks were also employed; themes were reviewed by a peer on the Doctorate of Clinical Psychology (DClinPsy) programme, and my academic supervisor. Both were able to offer an objective perspective given that they had no prior involvement in the project. Themes were also discussed with a senior practitioner in the service, in the absence of the commissioner.

Limitations

Several limitations exist. Firstly, recruitment difficulties and time constraints meant that the recruitment target was not met; it is possible that a larger sample would have allowed for more variation in the findings and increased representativeness of the target population. Similarly, though the team is relatively small, participants were recruited from feedback appointments with only two different clinicians, thus themes are not necessarily generalisable to all clinicians. However, it is expected that parents will have had contact with other clinicians during earlier stages of the assessment, and, certainly, with the broader processes within the service.

Further potential sampling bias is possible as a result of the recruitment strategy itself, as practitioners may have been less inclined to share the project information with parents' and carers' with whom it had been difficult to build a relationship. Moreover, it is possible that there was an element of self-selection in later stages of recruitment. For example, one prospective participant declined to take part as a result of feeling too overwhelmed after their child had received a diagnosis. As such, it may be that the sample only consisted of participants who felt positively about the outcome. Indeed, it is possible that this also positively skewed said participants' recollection of the experience.

Further issues with representativeness are apparent in that all parents in the sample were of children who received diagnosis of ASD (i.e. not ADHD, or a dual diagnosis). Whilst it could be argued that the parental experiences of both might be similar, given the overlap between the two conditions, the generalisability of the findings are limited in this way. In

addition, it is known that people of colour experience disadvantage in the assessment process (Begeer et al. 2009). However, all participants were of white ethnicity, thus the findings are not representative in this way. It should also be noted that this project explores the parental experience of one specific service, meaning that conclusions cannot be generalised beyond this.

Dissemination

This report was summarised in a poster and a presentation which were both shared at the University of Leeds DCLinPsy Service Evaluation Project conference in October 2022. The findings are also expected to be disseminated within SWYFT in relevant team and management meetings, and shared with the Trust Quality Improvement and Assurance Team.

Conclusion and Recommendations

In summary, the neurodevelopmental assessment service was generally well-received by parents. Findings highlighted strengths of the service as well as areas for improvement. It was particularly apparent that parents were most satisfied with the actual assessment itself; responses suggested that all three of their emotional, relational and informational needs were met at this stage. However, parents felt that their informational needs, particularly, could have been better met both before and after the assessment; additional information may have improved their confidence with regards to preparedness for the assessment, and ability to understand and adapt to their child's diagnosis afterwards. Several recommendations are suggested, as summarised in Table 2.

Table 2

Service recommendations

Themes and sub-themes	Recommendations
Theme 1: Before assessment	
Lack of clarity	<ul style="list-style-type: none">• Responses indicate that the initial appointment letter did not provide clear enough information on what the assessment would involve, and this appeared to link with parental anxiety. The letter could be amended to include further clarification about the following:<ul style="list-style-type: none">○ That the parent interview and the child assessment will take place in separate rooms, simultaneously;○ What will be asked of the parent on the day, and why;○ Expectations regarding approximate timescales and the potential for additional assessments.• Some participants received photos of the team, and some did not; it would be useful to ensure that the photos are consistently sent out to all families along with the appointment letter.• The content of the letter was felt to be reflective of an assessment with a younger child and may benefit from being adjusted to reflect a variety of assessment tasks, applicable to a wider age range.

Themes and sub-themes	Recommendations
Wanting to be able to prepare more	<ul style="list-style-type: none"> • The letter is addressed only to parents; responses suggest that, for some children and young people, this may leave them feeling overlooked. Addressing the child as well as the parents may be more inclusive. • Responses indicate that participants, knowing now what the assessment would entail, would have appreciated prompts in the initial letter to: <ul style="list-style-type: none"> ○ Read through their child’s red book to remind themselves of key events in the child’s early years; ○ Discuss their child’s early years with other family members to jog memory.
Theme 2: During Assessment A sense of calm	<ul style="list-style-type: none"> • Participants generally felt that the set-up and logistics of the assessment on the day worked well, with responses highlighting a number of strengths. The service should continue to ensure the following take place: <ul style="list-style-type: none"> ○ A calm environment; ○ The process was clearly explained; ○ Appointments were on-time, with good co-ordination of the parent interview and child assessment; ○ Parent able to speak honestly and openly due to being in a different room to the child; ○ There was enough time for parents to share information without feeling rushed.

Themes and sub-themes	Recommendations
“It felt like they cared”	<ul style="list-style-type: none"> • However, responses suggest that expectations and approximate timescales regarding the next steps could be more clearly communicated at this point; the service may consider taking more time to express this at the end of the appointment. • Responses highlight the importance of practitioners adopting a warm, sincere and caring approach, with parents feeling listened to, valued, validated and understood. This was reflected in the results as a particular strength of the service and staff should continue to work in this way.
A safe pair of hands: trust in practitioners	<ul style="list-style-type: none"> • A further strength of the service was that participants trusted practitioners and were reassured by their containing approach to the assessment which, overall, was thought to be thorough, comprehensive and fair. Responses highlighted a number of ways in which this was achieved, and which the service should continue to demonstrate: <ul style="list-style-type: none"> ○ Transparency and clearly communicated boundaries and expectations in the parent interview from the outset; ○ Clear, concrete and objective questions asked of the parent; ○ Reassurance that the parent may be contacted after the appointment if is not possible to complete the assessment in the given time; ○ An open-minded approach to the assessment, without preconceptions; ○ Asking about the child’s strengths as well as difficulties.

Theme 3: After Assessment

Themes and sub-themes	Recommendations
Feedback: “they went the extra mile”	<ul style="list-style-type: none"> • Responses indicate that, for a number of reasons, parents’ experiences of receiving the outcome of their child’s assessment was generally positive; the following points should continue to be implemented: <ul style="list-style-type: none"> ○ Detailed explanation of diagnostic outcome and rationale for this; ○ Space to discuss and expand on key points; ○ Advice shared in relation to ‘next steps’ and available sources of support, given the lack of funding for clinical post-diagnostic support and parental sense of “what now?”. • It may be helpful to more clearly communicate or remind parents of the remit of the service (i.e. diagnostic only) from the outset of the assessment, as responses suggest that this was a shock for some parents at the end. • The service may wish to consider whether referring to this appointment as ‘feedback’ is an appropriate reflection of the significance of this meeting for families. • Responses indicate that there may be a lack of process / inconsistency with regards to whether or not the child or young person is invited to this final appointment. It may be useful for practitioners to spend more time considering this with parents in advance of the appointment.
Wanting “something to take away”	<ul style="list-style-type: none"> • Upon leaving the feedback appointment, participants felt that the provision of some printed material would have been helpful, given that information can be difficult to process on the day, and that there may sometimes be a wait before receiving the final

Themes and sub-themes	Recommendations
	<p>report. The service may consider developing and sharing the following with parents in the feedback appointment:</p> <ul style="list-style-type: none"> ○ General information about the diagnosis and what this means; ○ Third sector organisations, websites and sources of support that can be accessed; ○ Advice about ‘next steps’, i.e. who to inform / actions that might be taken; ○ A brief, one-page letter to confirm the diagnosis so that the outcome can be immediately and formally shared with school, for example.
A clear and detailed report	<ul style="list-style-type: none"> ● Responses from parents who had received the report at the time of interview indicate that it was clear, detailed and user-friendly, though it may be beneficial for the service to consider ways in which the report could be made more concise in order to avoid repetition of some information. ● Parents valued the report being tailored, i.e. with use of the parent’s and the child’s own names. However, it was felt that the recommendations shared felt vague, thus the service may wish to consider the possibility of incorporating additional suggestions that are more tailored to the child and family’s needs. ● Whilst the prior context was appreciated, responses indicate a preference amongst parents for the outcome of the assessment to be included at the beginning of the assessment rather than the end; the service may wish to re-assess the current structure of the report and the needs of the audience.

Acknowledgements

A special thanks to all participants, and also to Pete Ruse from Family Voice Calderdale for his expertise and enthusiasm in the early stages.

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Appendices

Appendix A: Interview Schedule

➤ **Warm up – brief discussion around factual information**

- When was the assessment – concluded a month or so ago?
- Daughter / son / step son / etc?
- Did they receive a diagnosis or not?

➤ **Main body of questions about assessment process – not post-diagnostic support**

1. How did you find the assessment process itself?

- Looking back on the assessment as a whole, what sort of experience was it?
- Did any stages or parts of the assessment stand out for you?
- How thorough do you think the assessment process was?

2. As you went into it, how well did you understand what the assessment was going to involve?

- Arrangements – what, why, who, where, when?
- Was there anything else you might have wanted to know about or needed beforehand?

3. Was there anything in particular about the process that you think worked well?

- Did any particular part feel particularly helpful?
- e.g. interaction with staff, practicalities...

4. Was there anything in particular about the process that you think didn't work so well?

- Can you think of any part of the assessment that might benefit from improvement?
- e.g. interaction with staff, practicalities...

5. Was the assessment what you expected?

- Any surprises?

- Any part of it that didn't meet up to your expectations?
- Any part of it that exceeded your expectations?

6. What did you think of the feedback?

- How did the practitioner share the information with you?
- How clear or not clear was the report?
- How did you find the recommendations given?
- Would you have changed anything about the report?

7. Looking back, is there anything the service might have done to make your experience any easier?

- For you as a parent or carer?
- For your child?

8. Is there anything else you'd like to add?

NB: The text has been copied from an online format, therefore the formatting has changed slightly.



Neurodevelopmental Assessment Service

Introduction

Following our recent phone call, thank you for taking the time to find out more about this project.

This short survey will take you 10-15 minutes to complete. It includes two parts:

- Information about the project. This explains what the project is about, and how we will use your information.
- A consent form for you to agree to take part in this project.

About the research

An evaluation of parents' and carer's experiences of the Neurodevelopmental Assessment Service for children and young people in Calderdale

This is an invitation to take part in a project. So that you can decide whether to participate or not, it is important for you to understand why the project 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. If there is anything that is not clear, or if you would like more information, please find contact details at the bottom of the page.

A pdf copy of this information has also been emailed to you for your convenience.

What is the purpose of this piece of work?

The Calderdale Neurodevelopmental Assessment Team offers diagnostic assessments to children and young people where there are concerns regarding ASD or ADHD, or both.

Previously, there were two separate pathways for the assessment of ASD and ADHD. In 2020, the Covid-19 pandemic prompted consideration about how to streamline the service. As a result of this, the two pathways were combined to form a single assessment pathway.

The aim of this project is to understand the experience of parents and carers who have supported their child through the new assessment process. We hope that this will help the service to find out about which parts of the service work well, and where changes might be helpful.

Who is organising this piece of work?

The project lead is xxx xxx. I am in training for a Doctorate in Clinical

Psychology at the University of Leeds. I am independent of the Calderdale Neurodevelopmental Assessment Team.

I am doing this piece of work on behalf of South West Yorkshire NHS Foundation Trust (SWYFT).

Ethical approval has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (DClinREC 21-010).

Why have you been invited?

You have had the experience, as a parent or carer, of supporting your child through the assessment pathway from beginning to end.

We aim to talk with 6-10 parents or carers in total.

Do you have to take part?

No. Your participation is completely voluntary.

You can withdraw your consent and exit the project by either:

- Cancelling the meeting beforehand by emailing xxxx at xxxx@leeds.ac.uk;
 - Ending the interview and leaving the Zoom call;
 - or emailing xxxx up until **one week after the** interview. After this time, you will not be able to withdraw your data.
-

What do you have to do?

If you choose to take part, please continue to read through this information before completing the consent form on the next page.

After this, we will meet on the agreed date and time, via a video call on Zoom. The call will be between 30 and 45 minutes. It would be helpful if you could arrange to have an hour by yourself in a quiet room for the video call.

We kindly ask for just one parent or carer to join the video call. This is to make the analysis more manageable with the resources that we have available. Please feel free to talk with others before the video call to jog your memory and reflect on what the assessment process was like.

In the video call, first, there will be chance to ask any questions before we start.

Then, I will ask you questions about your experience of supporting your child or young person through their assessment with the Neurodevelopmental Assessment Service. Most of the questions will be 'open questions', which give you the chance to share as much or as little as you feel able to.

You can find more information below about how your data will be used for the project, and the strict confidentiality that you can expect from us. However, please be aware of the limits to this. For example, if we become concerned about the safety of yourself, your child, or others, or become aware of possible criminal activity, we will be required to share your information with other organisations. In such cases, we will strive to discuss this with you first.

Please note: *The Calderdale Neurodevelopmental Assessment Service is currently funded to provide diagnostic assessments ONLY. The service is not funded to provide post-diagnostic support. Because of this, most of the questions will focus on your experience of the assessment process ONLY.*

However, we do recognise that families are likely to have support needs following the assessment, and we are interested to find out more about this. We will ask you about your post-diagnosis support needs separately, at the end of the conversation.

You will not be asked to do anything else after this point.

What are the possible risks and benefits taking part?

Supporting your child through a neurodevelopmental assessment can be a upsetting, and it is possible that you may become emotional when sharing your experience of it. As a result, you may wish to contact the project team following the interview to discuss your concerns. Alternatively, other, external sources of support are also listed at the bottom of the page.

We do not anticipate that you will experience any other risks as a result of taking part. However, we do recognise that taking part in the project will require up to an hour of your own time.

Whilst there are no immediate benefits for yourself to taking part, we do hope that your contribution to this piece of work will help the service to develop and improve.

Will you be recorded, and how will the recorded data be stored?

Yes. The meeting will take place on Zoom. It will be recorded using Zoom's recording function. You can choose to have your camera switched off, if this is preferable.

Zoom produces 3 files when recording, one of which is audio only. On the day of recording, this audio file will be saved as an encrypted file on xxxx's OneDrive account - a secure university storage area permitted for highly confidential data by the University's Data Protection Policy.

The other two files containing visual data will be destroyed immediately.

How will the recorded data be used?

xxxx will listen to the recording and identify the themes in what you have said. She will make a note of quotes that illustrate those themes.

All notes will be typed and stored securely, and identifying information will be removed, such as your name, and your child's name, for example.

Themes in your data will be compared with themes in the data from other parents or carers, in order to find similarities and differences. It is common practice to do this with other members of the project team. This helps to make sure that the chosen themes reflect the data as accurately as possible.

Two Assistant Psychologists from the Neurodevelopmental Assessment Team will support this. They will not have access to any of your personal details such as your name, telephone number or email address. However, it is possible that they may recognise you from the sound of your voice, or any identifiable information that you may have shared during the meeting, such as reflections on unusual or standout experiences. However, they are also bound by a confidentiality agreement as part of their role in the service.

xxxx will then write about the themes in a report. No names will be used to identify quotes.

No other use will be made of the original audio recordings, and nobody else will have access to them, aside from xxxx's university academic supervisor (details below).

The original recordings will not be required for future projects. They will be destroyed when xxxx's university IT account is shut down upon completion of her studies (mid 2023).

What happens to your personal information?

During the video call, we will ask you to avoid sharing identifiable information where possible, e.g. your child's name. However, as mentioned above, we will take steps, wherever possible, to anonymise the data afterwards.

All of the contact details that we collect about you during the course of the project will be kept strictly confidential*. This information will be stored separately from the project data.

**During the interview, if the interviewers become concerned about the safety of yourself, your child, or others, or become aware of possible criminal activity, they may be required to share this information with other organisations. In such cases, the interviewer will strive to discuss this with you first.*

Where will the results of the project be made available?

We expect that the project will be completed in the final months of this year. At this point, it will be shared at an informal conference at the University of Leeds. It will also be submitted formally to the University.

The results will be shared in meetings with the Neurodevelopmental Assessment Team, including the multidisciplinary team meeting, and with the CAMHS Management Team. They will also be discussed in the CAMHS Neurodevelopmental Steering Group - a joint meeting between Clinical Commissioners, representatives from health services, education, and parents.

When completed, the report will be made publicly available on the University of Leeds website.

We emphasise that you will not be directly identified in any report or publication. Participant numbers will be used rather than names, and the names of children and young people will not be included. However, there is a possibility of you being identified if you share information about particularly unique or unusual experiences of the assessment. This is because these experiences may also be memorable to the staff working in the team, for example.

Please note that the project findings will likely be used to inform future projects.

Contact details for the project team

For any queries relating to the project itself, please contact xxxx, on xxxx@leeds.ac.uk. Please do also use this email address to inform us of any changes to your contact details prior to the meeting.

Alternatively, you can contact xxxx's academic supervisor, Dr xxxxxxxx on xxxxx@leeds.ac.uk.

Other sources of support

Should you need further support following the interview, the organisations listed below may be helpful. Additionally, please refer to the sources of support and recommendations given in your child's assessment report.

National Autistic Society

The UK's leading charity for people on the autism spectrum and their families, providing support, guidance and advice.

- <https://www.autism.org.uk/>
- Calderdale branch: 07798 617448 or calderdale.branch@nas.org.uk

West Yorkshire ADHD Support Group#

This group has been set up to support adults with ADHD and parents/carers of a child with ADHD (with or without a diagnosis) in the West Yorkshire area.

- <https://www.facebook.com/groups/216488425852125/>
- See also <https://adhduk.co.uk> for general information about ADHD.

Samaritans

"If you need someone to talk to, we listen. We won't judge or tell you what to do. People contact us with all sorts of concerns and what might be a small issue to you may be a huge issue to someone else."

- Call 116 123, 24hrs a day, 7 days a week, or visit <https://www.samaritans.org/how-we-can-help/contact-samaritan/> for more information.

Research Participant Privacy Notice

Purpose of this Notice

This notice explains how and why the University uses personal data for research; what individual rights are afforded under the Data Protection Act 2018

(DPA) and who to contact with any queries or concerns.

All research projects are different. This information is intended to supplement the specific information you will have been provided with when asked to participate in one of our research projects. The project specify information will provide details on how and why we will process your personal data, who will have access to it, any automated decision- making that affects you and for how long we will retain your personal data.

Why do we process personal data?

As a publicly funded organisation we undertake scientific research which is in the public interest. The DPA requires us to have a legal basis for this processing; we rely upon “the performance of a task carried out in the public interest” as our lawful basis for processing personal data, and on “archiving in the public interest, scientific or historical research purposes, or statistical purposes” as our additional lawful basis for processing special category personal data (that which reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic or biometric data, and data concerning health, sex life or sexual orientation).

How do we follow data protection principles?

- We have lawful bases for processing personal and special category data.
- Data are used fairly and transparently; we will make it clear to individuals what their data will be used for, how it will be handled and what their rights are.
- We only collect and use personal data for our research, for research in the public interest, or to support the work of our organisation.
- We only collect the minimum amount of personal data which we need for our

purposes.

- We take steps to ensure that the personal data we hold is accurate.
 - We keep your personal data in an identifiable format for the minimum time required. We take steps to ensure that your data is held securely.
 - We keep a record of our processing activities.
-

What do we do with personal data?

Research data can be a very valuable resource for improving public services and our understanding of the societies we live in. One way we can get the most benefit from this work is to make the data available, usually when the research has finished, to other researchers. Sometimes these researchers will be based outside the European Union. We will only ever share research data with organisations that can guarantee to store it securely. We will never sell your personal data, and any data shared cannot be used to contact individuals.

The project specific information will include more detail about how your data will be used.

Your rights as a data subject

Because we use personal data to support scientific research on the public interest, individuals participating in research do not have the same rights regarding their personal data as they would in other situations. This means that the following rights are limited for individuals who participate, or have participated in, a research project:

- The right to access the data we hold about you.
- The right to rectify the data we hold about you.

- The right to have the data we hold about you
 - erased. The right to restrict how we process your data.
 - The right to data portability.
 - The right to object to us processing the data we hold about you.
-

Data security

We have put in place security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

Retention periods

We will only retain your identifiable personal information for as long as necessary to fulfil the purposes we collected it for; we may then retain your data in anonymised or pseudonymised format.

To determine the appropriate retention period for personal data we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

Additional notices and guidance/policies

The University has also published separate policies and guidance which may be applicable to you in addition to other privacy notices:

- Current staff privacy notice
- Current students privacy notice

The Research and Innovation Service website has other relevant policies and guidance(<https://ris.leeds.ac.uk/research-ethics-and-integrity/good-research-practice/>)

Communication

In the first instance please contact the researcher who your initial contact was with. You may also contact the Data Protection Officer for further information (see contact details below).

Please see the Information Commissioner's website for further information on the law.

You have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. Please see the ICO's website.

Concerns and contact details

If you have any concerns with regard to the way your personal data is being processed or have a query with regard to this Notice, please contact our Data Protection Officer (Alice Temple: A.C.Temple@leeds.ac.uk).

Our general postal address is University of Leeds, Leeds LS2 9JT, UK.

Our postal address for data protection issues is University of Leeds Secretariat,
Room

11.72 EC Stoner Building, Leeds,
LS2 9JT. Our telephone number is
+44 (0)113 2431751.

Our data controller registration number provided by the Information
Commissioner's Office is Z553814X.

This notice was last updated on 20 February 2019.

Thanks for reaching this point!

Appendix C: Consent Form

NB: The text has been copied from an online format, therefore the formatting has changed slightly.

Consent to participate

Thank you for agreeing to participate in this project.

Please read the following statements and tick the boxes if you agree. Agreement with all statements is necessary in order to take part. If you need more information about any of the below, please email xxxx via xxxx@leeds.ac.uk.

You can download a copy of your completed consent once you have submitted your responses. A copy will be held by the project team in a secure online storage area for the duration of the project.

1. **Project information** I confirm that I have read and understood the information explaining the research project, and I have had the opportunity to ask questions about the project. *

Required

Yes

2. **My participation** I understand that my participation is voluntary and that I am free to withdraw, without giving any reason, up until one week after the interview has taken place. I understand that I can do this by emailing xxxx via xxxx@leeds.ac.uk, and that this will not have any negative consequences. Alternatively, I can withdraw by cancelling the meeting in advance of it, or ending the Zoom call during the interview. I understand that, should I wish to withdraw from the study, my data, including my completed consent form, audio recording file and analysis documents, will all be destroyed. In addition, I understand that this project only requires me to share information that I am comfortable in sharing. *

Required

Yes

3. **Confidentiality** I understand that members of the research team will have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential.

* *Required*

Yes

4. **Agreement to take part** I agree to take part in the above research project and will inform xxxx by emailing xxxxx@leeds.ac.uk if my contact details change.

Required

Yes

5. Your name: * *Required*

To submit the form, please be sure to press the 'finish' button below. You will then see a confirmation message on the next page.

Many thanks for agreeing to participate in this research.

If you want to keep a copy of your completed consent form, please download it using the link above.

As discussed on the phone, you will be sent an email invitation for the Zoom meeting over the next few days. The meeting will take place on the date and time that we agreed.

I will also send the Zoom link again on the morning of the meeting, for ease.

Many thanks once again, and I look forward to speaking with you.

Appendix D: Interview Summary Template

Participant number: Date of data collection: Date of analysis:
Before the assessment
Prior explanation
During the assessment
Practicalities
Interaction with staff
Experience
Expectations
After the assessment
Feedback appointment
Report
Additional comments / other observations

Appendix E: Matrix Template

Domain	Ppt 1	Ppt 2	Ppt 3	Ppt 4	Ppt 5
Before the assessment					
Prior explanation					
During the assessment					
Practicalities					
Interaction with staff					
Experience					
Expectations					
After the assessment					
Feedback appointment					
Report					
Other					

Appendix F: Final Summary Matrix

Domain summaries	Ppt no.	Example quotes and further information
BEFORE THE ASSESSMENT		
<p>Lack of clarity Initial correspondence didn't provide clear enough information on what the assessment would entail / arrangements for the day. Not knowing what to expect left parents feeling anxious, under pressure and fearing negative evaluation.</p>	All	<ul style="list-style-type: none"> • "It wasn't clear that the child would be in one room and parents in another – it would've been good to have been able to let the child know beforehand" (2) • "Had to read it a few times... I wasn't 100%" (1) • Wasn't aware of what would be asked of as a parent (1,4, 5) • "I'd like to have as much information at the start as possible – but that's just personal preference" (2) • Would have liked more information about the average timescale / what to expect in terms of multiple appointments or just one (2, 3) • Thought there would be more people in the room... "felt like I was going for a job interview" (5) • The need for bringing the red book could be explained to reassure parents: "I felt like I was being checked on" (1) • "It's important, there's a lot resting on this meeting but didn't know really what it'd involve / I was nervous, I didn't sleep the night before" (5) • Some parents received photos of staff team which was useful), whereas others didn't, and they felt this would have helped to "put a face to the service" (1) as not knowing can be uncomfortable... "It's about making people feel comfortable before they go" (1) • Yet - the importance of striking a balance between providing enough information, versus too much, e.g. if had have known more, could have been stressful and anxiety provoking in the lead up (4) • Could it be addressed to the child too? "...with Autism... she sometimes feels overlooked... and I just think a separate piece of paper, a letter, just something – it means the world to them" (5) • The wording seemed to be aimed at young people e.g. with mention of soft play tasks which didn't feel appropriate for teenagers – who is the service user? (5)
<p>Wanting to be able to prepare more Some participants felt that they would have liked to have been able to prepare more prior to the assessment.</p>	1, 2, 4	<ul style="list-style-type: none"> • Could have prompted us to do things before the assessment such as asking family members if anything stands out from memory: "could ask family members if anything stands out in their minds... that they wouldn't have wanted to say at the time"(4) • "there was nobody else to go into that meeting with me to say what [child] was like in their early years, there is only me" • or looking through the red book to jog memory: "looking through it reminded me of things – it can be hard to remember off the top of your head" (1) • Didn't realise there'd be so much delving into previous medical history - we could've been more prepared with having stuff to hand" (2)
DURING THE ASSESSMENT		

<p>A sense of calm The set-up on the day worked well and the environment was calm and welcoming, however communication around expected timescales may have been clearer.</p>	<p>1, 2, 3, 4</p>	<ul style="list-style-type: none"> • A calm environment (1, 4) • Process was well-explained on the day (1, 3): “I felt so well-informed from that point” (3) • Being in a separate room to the child meant that I could talk openly and not worry about child hearing (1) • Appointment times worked well, i.e. length felt appropriate (1) and they began on time – which was helpful in terms of the child benefiting from predictability and routine (2) • “After the initial assessment appointment, we thought it’d all be wrapped up in a couple of weeks” ... “you’ve been on the waiting list that long, and you finally get to have the initial assessment and you think woah a couple of weeks... and we’ve got to the end of it – I know that timescale is totally unrealistic (now), but it’d have been nice to have had a... [something to] guide our expectations” (2) • “It seemed like they worked well as a team” (1) in terms of coordinating timings • Felt contained with regards to timing (all). Didn’t feel rushed (2, 4) / “they weren’t clock-watching”, with space to talk about things as appropriate (3) / “I left the room feeling as though I got my point across (5).
<p>“It felt like they cared” Practitioners were kind, warm and sincere, and participants felt comfortable and reassured as a result.</p>	<p>All</p>	<ul style="list-style-type: none"> • Feeling listened to: “They wanted to hear my views as a parent” (1) / “It felt like they cared” (2) / “even the strange little things that you’d think wouldn’t matter, they listened to and noted” / “they didn’t make me feel like a neurotic mum” (3) • Understanding (4) / “concerns were validated” (1) • Made to feel comfortable (1) / “She made us at ease” (5) / “I was reassured – there was no pressure to remember” (4) / They were “human... it felt like they were just with you” / “they were just smiley and open” (1) • “All the people we dealt with were all really friendly, really understanding... couldn’t have asked for better really” (2) • “Couldn’t praise her enough for how she was with me” (1) • “Reassuring / respectful / polite / kind / non-judgemental” (1) • “Approachable / thoughtful” (3) • A friendly and welcoming reception (1, 2, 4)

<p>A safe pair of hands: trust in practitioners Practitioners adopted a transparent, respectful and clearly bounded approach to the parent interview which helped participants to provide the necessary information. Relatedly, participants also felt that the assessment was thorough. However, the unexpectedly in-depth nature of the interview was difficult for one participant.</p>	All	<ul style="list-style-type: none"> • Boundaries to the session explained in terms of practitioner will stop you when they have enough information: “they let me go off when I needed to and then drew me back in” (1) • Re-phrased questions when I didn’t understand (5) • Objective questions allowed for objective answers – had worried about how I would be able to comment on child’s presentation (5) “Any questions we had were answered to the best of their ability” / “really knowledgeable and professional” (2) • Transparency: clear on what they were needing, wanting, expecting, looking for (3) / “they did what they said they’d do and stuck to their word (3) • Thorough (1, 2, 3) • Staff were “perceptive” (1) / “it started the minute they said hello” – observations made from the outset. “...because [they] were instantly watching how she behaved, they picked up on it, and I liked that because I thought, well, I feel a bit at ease” (5). • Reassuring as didn’t want child needs to be overlooked / elements of presentation to be missed (5) • “...reassured that I would be contacted afterwards if we didn’t cover everything” (1) • Questions asked about strengths as well as difficulties – a full picture of the child (1) • An honest assessment: “it felt like there were no preconceptions” (1) / “they were open minded” (3) having picked up on discrepancies between school’s account and parent’s account / It was clear that notes had been read prior (1) • – though one participant commented on feeling “knocked sideways” and “felt the pressure” having not known how in-depth the assessment would be (4). • “Not quite sure what I expected but it was better than what I expected / Didn’t expect them to be so thorough (3) / “It was a lot better than I thought it was going to be” (5)
AFTER THE ASSESSMENT		
<p>Feedback: “They went the extra mile” Participants were reassured by practitioners in the feedback appointment and were grateful for the amount of information and level of detail shared.</p>	1, 2, 3, 5	<ul style="list-style-type: none"> • Lots of time spent at end of appointment sharing information and sources of support; “they went the extra mile” (2) • Appreciated some suggestions for action steps being shared (1) • “Space to expand on information” / went through the whole thing with us and checked some things with us too (3) • “They put me at ease” (3) • Staff were reassuring and comforting and discussed observations with us in detail (5) • “they went through every point of it and explained absolutely everything as much as they could” / “for what funding allowed her, she could not have done any more” (5)

		<ul style="list-style-type: none"> • “the word feedback – it sounds so office-like, that’s what office people say in emails / feedback usually means they want to know what’s gone wrong” - “a follow-up appointment” instead? (5) • “it’s a big thing in a family’s life to be told your child’s autistic” / “it’s a lot more important than the word ‘feedback’” (5) • Difficult experience with child being present for this, highlighting difficulties – felt like a character assassination. Could it have been an appointment of two halves? Parent first then child joins shortly after? (4) • Wish we’d have known about the lack of post-diagnostic support from the outset – it was a shock at the end – had different expectations about the service offer (5)
<p>Wanting “something to take away” Some participants found it difficult to absorb the information provided in the feedback appointment and spoke of the possible utility of having a booklet / document to take away to support with this / to enable them to formally share the diagnosis with school.</p>	All	<ul style="list-style-type: none"> • Long wait to receive report (1, 2), versus being received in a timely manner (3) • Could there be a one-page summary or cover letter given out to confirm diagnosis immediately? (1) / A letter came in the post after the appointment confirming diagnosis whilst report is being prepared – could that not be given out during the appointment? (5) • Having a leaflet / booklet or something to take away from the appointment would be useful – having to wait for the report is frustrating as you’re wanting to share the outcome formally with school and it’d be useful to have something to refer to in the interim (4) • Difficult to absorb information in appt; if we could be left with a booklet to take away? - “To be able to have something instantly because you feel useless, I go home and yes, my daughter’s autistic but now what do I do... but if I had the writing in my hand and places I could go...” (5) / “I felt like I’d won the lottery but it’s in pesos” (5)
<p>A clear and detailed report The clarity and level of detail in the report was generally appreciated.</p>	1, 2, 3	<ul style="list-style-type: none"> • Report “easy to digest and read” (1), very clear and detailed (2, 3), though a little “repetitive” (2) • Included “things that even I as a parent hadn’t picked up on” (3) • Specific phrases were expanded upon e.g. terms parents might not understand (3) • Use of child’s NAME and parent’s name “this is the first report I’ve ever had that’s mentioned both our names” – acknowledging people as people rather than just a number: “a real positive” (1) • Can the diagnosis be at the beginning rather than the end? (1, 2) • Recommendations were really helpful (2) • Keen for more specific recommendations where possible, mostly felt vague (1)