



Guidelines to Assist in Diagnostic Assessments of Autism in Women: A Delphi Study

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Background

- There is a higher rate of autism in males than females (Loomes et al., 2017).
- Autistic women are less likely to receive a diagnosis of autism than men with similar levels of autistic traits (Dworzynski et al., 2012) and are more likely to have been previously misdiagnosed with other conditions such as personality disorders (Lai & Baron-Cohen, 2015).
- Several hypotheses regarding sex differences in the prevalence of autism have been proposed, including the Female Autism Phenotype, which describes a behavioural expression of autism that is more common in females (Hull et al., 2020)

Background

- Sex differences in autistic presentation may also be influenced by male bias in the diagnostic criteria and clinician knowledge (Lockwood Estrin et al., 2021).
- Giarelli et al. (2010) - males were more likely to have an autism diagnosis than females despite both sexes having documented autism symptoms in educational and clinical records. This may result from an 'interpreting bias', where the observed experiences differ from the expected behaviours dependent on sex.
- Cridland et al. (2014) - healthcare professionals lack of awareness of autism in females due to a perceived higher incidence of autism in males, there is a lack of knowledge of the clinical nuances of the autistic presentation in females, and as a result are reluctant to diagnose a female as autistic.
- Cumin et al. (2021) - experienced clinicians found it difficult to differentiate autism from trauma and borderline personality disorder. These clinicians used individually developed techniques to reveal signs indicative of autism in women that were not largely captured by standardized instruments.

Aims

We know women and girls can present with autism differently.

However, this research isn't being translated into screening and diagnostic tools and guidance.

Anecdotally, we know that clinicians are changing their practice within diagnostic assessments to accommodate women and girls.

So we decided to ask autistic women and girls about their experiences of assessment, and ask clinicians what adaptations they are making within their assessments.

We will collate these findings and translate into guidance.

Study Development


Phase 1

- “Put Autistic Women and Girls at the Heart”: Exploring the Experiences of Autistic Women during Diagnostic Assessments in the UK

Phase 2

- Guidelines to Assist in Autism Diagnostic Assessments with Females: A Delphi Study





Autistic Women and Girls at the Heart: Exploring the Experiences of Autistic Women during Diagnostic Assessments in the UK

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Aims



The focus groups aimed to explore the experiences of autistic women in the UK during their diagnostic assessments and understand what they considered important for diagnostic assessments of females.



These findings will be used to inform the Delphi study, and ensure autistic women's voices are heard within this process and directly influence guidance.

Method

Participants

- Volunteer and snowball sampling was used. Adverts for the focus groups circulated on social media and shared by autistic charities/organisations.
- For data saturation, we aimed to conduct two focus groups with six to eight participants in each group (Hennink et al., 2019).
- Initially, 10 autistic women volunteered for the focus groups. However, attrition was high due to a lack of compensation being offered for participation.
- Thus, four autistic women engaged in one focus group. The four participants were aged between 22 and 52 years (M=41 years).

Materials

- The focus group was a semi-structured interview lasting 90 minutes on MS Teams.
- Questions for the focus group were developed by the research team based on the research aims.
- The participants were asked questions about their experience of the autism assessment, such as what they wanted the assessor to know about them and what questions they thought were important to ask, as well as a question about what features of autism, specific to women, were or should have been assessed.

Method

Procedure

- Interested participants were emailed a consent form and a questionnaire collecting information about the context of their diagnostic assessment (e.g., referral source, tools used, and assessment location).
- The focus groups were facilitated on MS Teams.
- Group expectations outlined at the beginning and end of the focus group.
- The length of the focus group was extended (from 60 to 90 minutes) to allow participants to sufficiently elaborate and reflect. Once all set questions had been asked, facilitators opened the space to participants if they had anything else to add.

Ethical Considerations

- Ethical approval was obtained from the St Andrews Ethical Committee.
- Taking part was voluntary and all participants provided written consent after being provided with the study information.
- Participants were aware of their right to withdraw from the study at any point without explanation; they would not be able to withdraw data provided prior to leaving the focus group or after the focus group had ended, as this would prevent an understanding of the dialogue between participants.

Data Analysis

- The focus group transcript was analysed by two of the research team, using thematic analysis (Braun and Clarke, 2006).
- Thematic analysis was chosen as it is a useful and flexible method of understanding participants' experiences, views and opinions (Braun and Clarke, 2006). This involved six stages:
 1. familiarisation with the data
 2. generating initial codes
 3. searching for themes
 4. reviewing themes
 5. defining and naming themes
 6. producing the outcome report
- Each transcript was read by two researchers independently, with each noting potential themes and impressions of the data. Initial codes were then generated which were then combined into initial themes collaboratively by the two researchers, with consideration of inter-rater reliability. The codes were discussed with the wider research team and the themes refined.
- It was felt that data saturation for the discussion within this specific focus group is present.

Results - Themes

Thematic analysis identified three overarching themes and subthemes:

1) Experience of the Assessment

- 1.1 The Assessment as Stressful
- 1.2 Practical Aspects of the Assessment
- 1.3 Post-Diagnostic Support

2) Gender-Sensitive Assessment Content

- 2.1 Tools used
- 2.2 Context of the Assessment

3) Clinician Characteristics and Skills

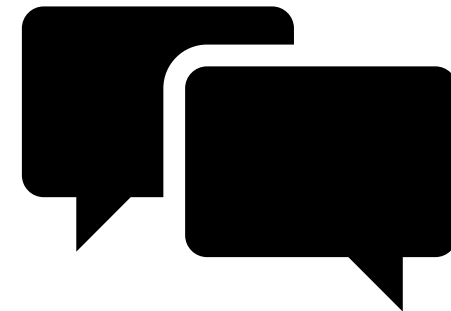
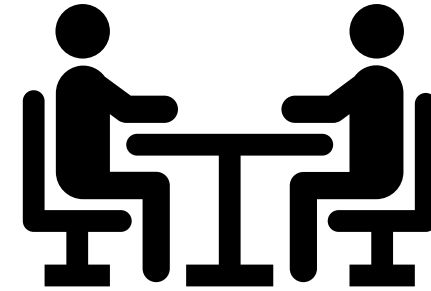
- 3.1 Clinician Characteristics
- 3.2 Specialised Clinician Training
- 3.3 Wider Training of Professionals

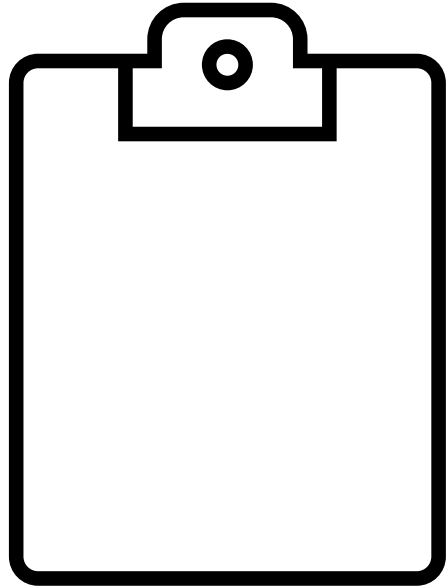


1) Experience of the Assessment

1.1. The Assessment as Stressful

- Three of the participants described the assessment process as stressful. This included the impact on personal responsibilities, such as having to take time off from school for appointments.
- Participants described feeling “judged” and as though they were being “tested”.





1) Experience of the Assessment

1.1. The Assessment as Stressful

- “The ADOS-2 (a standardised tool for observing autistic traits; Lord et al., 2012) was described to be patronising and demanding. When discussing the ADOS-2, Sarah stated:
- [The ADOS is] aimed for children and it was really patronising. And I had to read a book about flying frogs. I had to make some imaginative story with random objects. I placed bricks in a certain random order, and to be fair, I’m feeling quite emotional about it now. The hoops I had to jump through was really quite stressful”.

1) Experience of the Assessment

1.1. The Assessment as Stressful

- The language used during the assessment was reported to be uncompassionate and at times, felt like bullying. For example, when talking about experiencing bullying as a child, Sarah said ***“And then you are then bullied by adults trying to determine whether you can have friendships or not”*** (during the assessment).
- The phrasing of questions was felt to be critical and judgemental. Harriet discussed being asked about her understanding of a friend compared to an acquaintance and that it felt as though the undertone of the question was ***“you don't have any friends. They're not really friends. They can't deal with you”***.
- The use of the words ***“tool”*** and ***“test”*** were described to be ***“painful”***. Participants recommended that the phrase “assessment process” may be more compassionate as it reflects the process they are going through, rather than just being “assessed”.

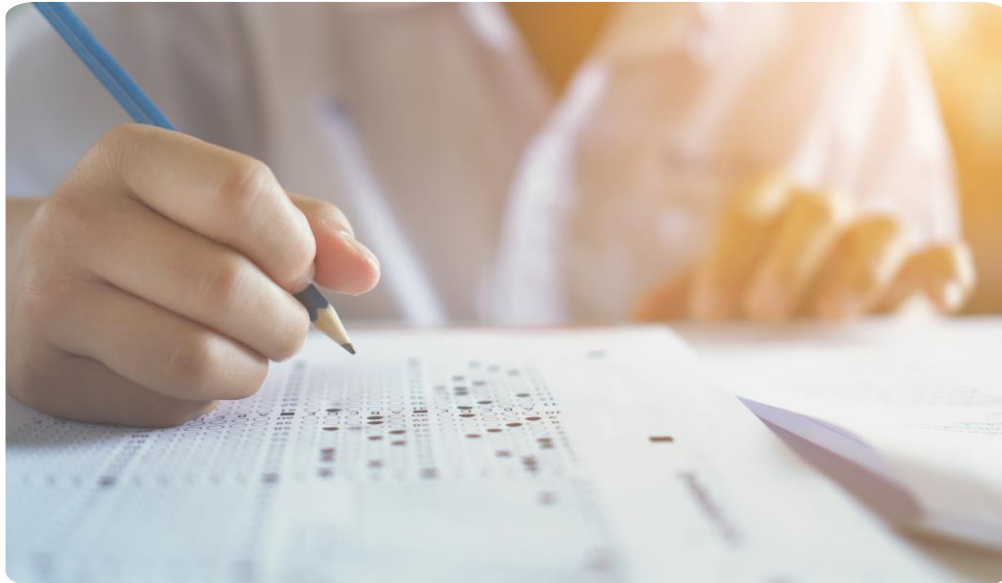




1) Experience of the Assessment

1.1. The Assessment as Stressful

- Ruth identified positives in the assessment process, in that it allowed her to **“unpack”** past experiences and better understand these within the context of autism. It was suggested by participants that the assessment needs to be more strengths-based. Alexis further stated:
 - ***“I think to also acknowledge the importance of clinician discretion within it and particularly as we look [to] more at strength based assessment rather than deficit based assessments. But I think put autistic women and girls at the heart of this and having a project that co-creates it with autistic clinicians is key”.***



1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- All participants reported to have preferred an online assessment, in that it helped with childcare and was more accessible.
- For instance, when describing her assessment being conducted via Zoom, Alexis said ***“A lot of women have kids... So I think that was really helpful”***. Sarah felt that having face-to-face appointments was not ***“neurodiverse friendly”*** and Alexis stated that it is ***“the needs of neurotypical people to have face to face interaction”***.
- When describing her face-to-face assessment, Sarah explained that it was at ***“strange place with a barrier. [She] didn’t know how to get in, didn’t know how the process worked, had very little information prior to it”***, later describing this to have been an ***“emotional rollercoaster”***. Sarah later stated, ***“We need information beforehand”***.



1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- There was a discussion about the length of the assessment. Sarah described having four assessment sessions and that the assessment process was ***“a long stretched out process”***.
- There were several references to a desire to have multiple assessments or re-assessment in the future to ensure autistic individuals receive the right support, with Sarah stating she wanted *“to be reassessed further down the line to see what, you know, challenges in life and what support to put in place”*.



1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- Additionally, Ruth explained:
 - *“[It] doesn't need to be just one assessment. I mean, for anybody that masks cause’ some blokes do mask as well, but particularly for women who mask, it needs to be that first assessment. [Then,] it needs to be a couple of years and a reassessment. It needs to be a couple of years... especially for people who diagnosed in later life for it to actually be helpful and actually support us in getting the help we need, it can't just be. ‘We saw you on Tuesday. You thought you might be autistic? We told you on Wednesday you were, but you were all OK because you were masking’”*

1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- Alexis preferred having two clinicians. She explained,

“Best practice is to have two clinicians assess. I quite like that as well because you sort of worry they might get it wrong, and having two was reassuring”.

- Participants provided several recommendations for informant contributions. It was recommended by participants that clinicians be mindful of the validity of informants, as school informants (e.g., teachers) were felt to be less reliable, whilst family and friends were felt to be better informants.
 - Alexis said that *“the school had said I was a high academic achiever. They didn’t observe anything”*. This was echoed by Harriet, who was diagnosed with autism as a teenager:
-

1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- *“They got my school involved and they did a school visit and they spoke to a few of my teachers and I've always been a high achieving student. I've got into [University]. So like context of where I was doing academically and all of my teachers said, well, she's intelligent, she gets good grades. So there's absolutely no signs of this student struggling. And I was like, yes, there is. There is many, many signs and that's that same academic year my mother had had a conversation with the school because ... my mental health. And I was like self-harming at the time, I wasn't eating enough food and they had this meeting with school. But my school just went well. Grades are good. So therefore the child is good”.*



1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- Participants wanted information provided by informants to be shared with them, prior to diagnosis, to cross-check the accuracy. This is reflected by Harriet, whose mother was interviewed during the assessment. Her mother described a conversation between them, but this was not discussed with the client herself. She explained:
- ***“My mother described the situation to the assessor. They were having a conversation with her and they didn't ask me about the situation... But in the report they were like [provided context on a situation, redacted for privacy] and didn't realise that this wasn't appropriate and without asking me my take on it. They very much phrased it in the report of you've misread a social situation. You've done something wrong and I felt judged by them for it... I felt like I couldn't be honest with [the assessors afterwards] about what my experience of that situation was and the emotions involved in it because I felt they didn't understand”.***



1) Experience of the Assessment

1.2 Practical Aspects of the Assessment

- Ruth provided an example of a positive experience, where informants had been involved at different points during the assessment:
- ***“I was very lucky in the fact that the clinician who did my initial appointment, who also spoke to my mother as well as you know me, she spoke to me on my own, me and my partner, and then my mother on her own, and then all of us together, she was brilliant”.***
- Ruth also stated that she would have preferred to write answers to questions than answer verbally in an interview, though was referring to assessments more generally, as opposed to the autism assessment specifically.

1) Experience of the Assessment

1.3. Post-Diagnostic Support



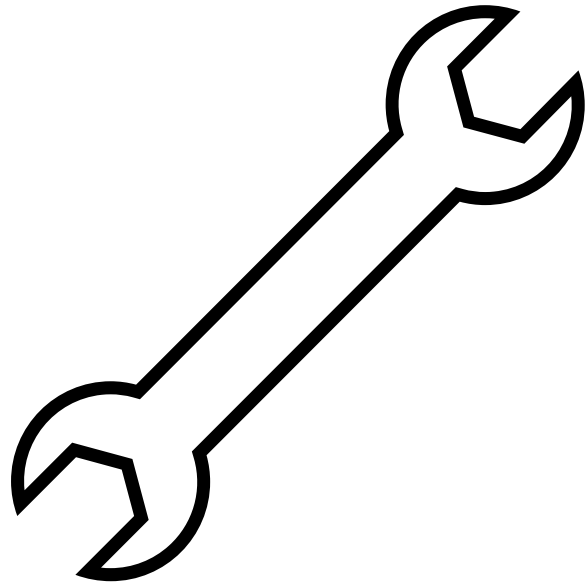
Participants described negative experiences of post-diagnostic support. Harriet explained that she *“got the diagnosis and then never heard from [the service] again”*. Sarah stated:

“You've just shattered someone's life because we've been living a lie and then be left to it” and *“It's not necessarily all about that assessment. It's about the aftercare and continued support”*

2) Gender-Sensitive Assessment Content

2.1 Tools Used

- Participants raised concerns about the validity of the assessment tools. Participants commented that the tools used in the assessment are used for everyone, regardless of age and gender, which was felt to be negative. For example, Harriet noted that she had the same assessment when she was 14 as a peer who was 6 years old. She stated:
 - ***“They were using very similar sort of assessment methods regardless of age... If you are at the age where you can read and write, it was the same all the way up to 18”.***
- Additionally, participants discussed how the assessment tools may incorrectly miss imagination abilities. Alexis suggested that aphantasia (the inability to form mental images of objects that are not present; Zeman et al., 2015) would impact on the imagination tasks. When reflecting on the assessment report, Ruth stated:
 - ***“Apparently I have limited to no imagination. I’m a role player who has been a role player since I was 18 years and have regularly spent my time playing two or three different characters a week”.***



2) Gender-Sensitive Assessment Content

2.1 Tools Used

- Participants also reflected on how the tools used are based on the male presentation of autism. Sarah stated that *“everything had been geared up to the boys”* and Alexis stated that female-specific questions were not being asked *“because of the skew of the research towards men and boys when designing these assessments”*. Alexis made recommendations for redesigning tools, stating:
 - ***“[There] needs to be research project commissioned specifically to redesign, because these tools and principally rooted in research in boys and men, they haven't been created with autistic girls and women...”***
- Masking was described as a barrier to diagnosis and that women can be more complex to diagnose as a result. Understanding the presence and impact of masking was reported to be important for diagnosis and self-understanding. It was also described to be important for understanding support needs. For instance, Ruth reported that there is a misunderstanding that because someone is masking, they can cope. She stated:
 - ***“Having unpacked all that masking and having realised exactly how my autism affects me... I cannot apply for anything that would give me help or support because my diagnosis letter basically says [I'm] fine, [I'm] not fine”***.

2) Gender-Sensitive Assessment Content

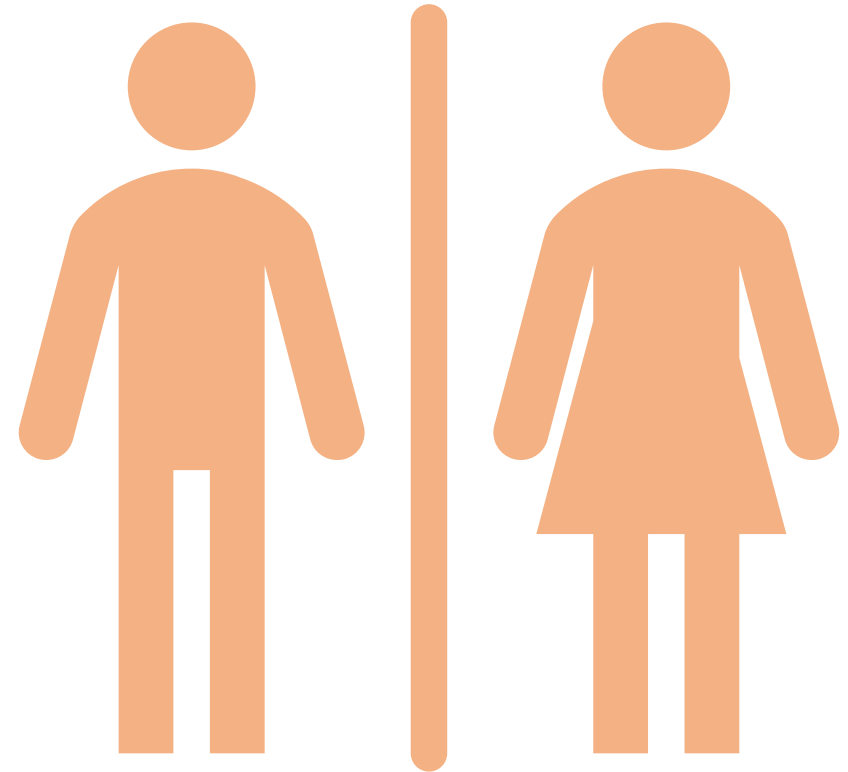
2.2 Content of the Assessment

When discussing questions that would be useful to ask in the assessment, participants identified questions about female-specific issues and questions about the female presentation of autism.

Regarding female-specific issues, participants want clinicians to ask about the client's experiences of

- Periods
- Sex
- Menopause,
- Sexual abuse/exploitation.

Alexis stated that asking about sexual exploitation and abuse ***“should be absolutely mandatory”***. It was suggested by participants that hormones can impact on the presentation of autism, such as leading to difficulties with memory and concentration.





2) Gender-Sensitive Assessment Content

2.2 Content of the Assessment

- Participants also suggested that autistic females relate to sex differently to males, and that the experience of periods and hormones is different in autistic females compared to non-autistic females.
- It was suggested that tracking and monitoring periods could inform the assessment ***“because of the extent to which hormones do impact you in a way that can be quite different in neurotypical people (Alexis)”***. For example, Sarah described having ***“heightened senses”*** during her menstrual cycle.
- Alexis explained her ***“relationship with sex was very, very different to my peers in my late teens and early 20s”*** and expanded that sex was ***“very transactional”***. She stated that: ***“[A] lot of autistic women do use sex quite differently and the same with periods. My experience of the pain of periods and the whole hormonal changes were very different. So I think there's some questions that could be asked that could be very enlightening, which are not being asked because of the skew of the research towards men and boys when designing these assessments”***.

2) Gender-Sensitive Assessment Content

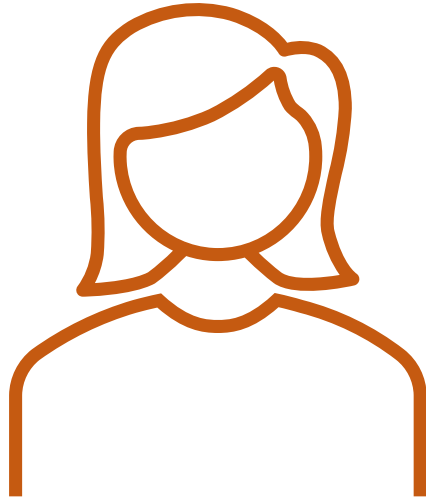
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2. Gender-Sensitive Assessment Content

2.2 Content of the Assessment

- Participants wanted clinicians to ask questions about the female presentation of autism, such as differences in stimming, special interests and masking.
- Harriet noted that her diagnostic report stated she did not display repetitive behaviours because they did not observe **“hand flapping”** but that her stimming consists of playing with her hair, which would have been more subtle in the assessment.
- All participants agreed with her statement that **“[hand flapping is] not the only way you can stim”**.
- Harriet also spoke about how her interests were felt to be typical of a **“little girl”** and that the assessors **“never looked into the extent of it the hyperfixation and but [they would have] if it [were] trains”** (e.g., more male-biased interests). This was also linked to masking, with Sarah stating,
 - **“Because of the gender injustice, so the expectations of boys and men is totally different to women and girls, and that then puts that pressure on us to mask”**.



3) Clinician Characteristics and Skills

3.1 Clinician Characteristics

Having a female clinician was reported by Alexis to be preferable, who stated:

- *“I also liked the fact that it was two women who were assessing me because I had been worried about a poor understanding of how autism can present differently in women compared to men and boys” further stating “I found that [having female assessors] put me at ease and we could talk through those worries”.*

Additionally, participants recommended that autistic clinicians should be involved in the diagnostic process. Sarah stated:

- *“Why is it we have to have neurotypicals assessing and validating our lives? ... I would say that would have to be on any kind of diagnostic board that you have that representation of what you’re actually, you know, recognising”.*

3) Clinician Characteristics and Skills

3.1 Clinician Characteristics

- It was felt by participants that autistic clinicians would be better able to identify autism in others due to their lived experience. Ruth felt that having autistic clinicians would be ***“the fastest tool and fastest way to cut down the waiting list”***.
- Ruth made reference to the clinical background of the assessing clinician. She explained,
 - ***“They had me back in for the testing, which was given to me by a speech therapist trained to give the test rather than a clinician who I clearly offended by questioning her suitability”***. She later went on to say ***“I feel, I was let down was by a [speech] and language therapist trained to give the test as opposed to a clinician who could actually tell what was going off during the test”***.

3) Clinician Characteristics and Skills



3.2 Specialised Clinician Training

- Participants wanted clinicians to have had sufficient training on identifying autistic traits in women:
 - ***“The problems about the skill of the people assessing [is] because I think for women and girls, there is more complexity there where we typically learn to mask and can be more adept at masking ... It's not so hard to get a qualification to do this to us, but it's a real skill to understand women and girls. And I think there needs to be some sort of, I don't know, advanced qualification or a recognition that you need a more highly skilled clinician involved in order to really understand the person in front of you and not to make assumptions” (Alexis).***



3) Clinician Characteristics and Skills

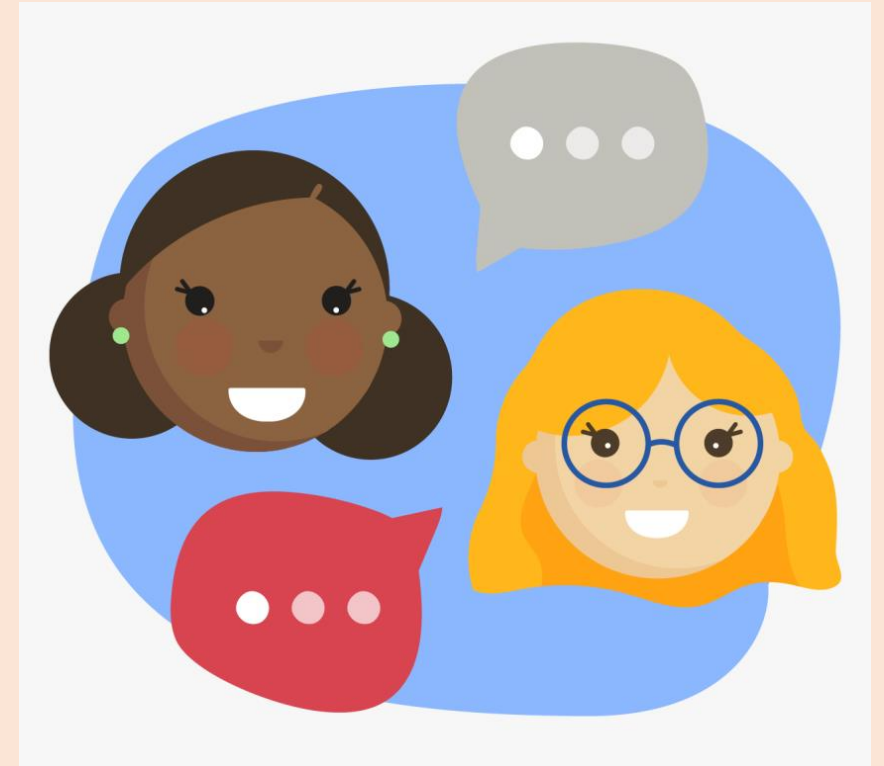
3.2 Specialised Clinician Training

- Participants wanted clinicians to have received training on differences in friendships and stimming, the influence of gender roles and expectations, as well as being able to identify and understand masking. It was also recommended that assessing clinicians receiving training to understand the prevalence and impact of sexual abuse in autistic women. For example, Harriet mentions:
 - *“Further training on for people who get diagnosed like this is what stimming and masking and all these sort of things, especially just look like in girls. And [that] it's not just hand flapping”*
- Alexis also stated:
 - *“I think for women and girls, there is more complexity there where we typically learn to mask and can be more adept at masking... it's not so hard to get a qualification to do this to us, but it's a real skill to understand women and girls. And I think there needs to be some sort of, I don't know, advanced qualification”*
- Participants discussed that it is important for clinicians to understand what they are observing and to ask the ‘right’ questions. Participants repeatedly recommended that clinicians receive ongoing training on autism and autism in females specifically.

3) Clinician Characteristics and Skills

3.2 Specialised Clinician Training

- Participants also discussed clinicians needing broad skills for conducting assessments.
- Ruth reflected that clinicians should be trained to understand the cause of behaviours. She explained that she was assessed to have limited imagination, wherein she felt in reality, she had disengaged from the assessment, which was not identified by the assessor.
- Sarah also described that the clinician jumping around and interjecting during the assessment led to increased stress.
- Participants discussed that clinicians need to be able to provide support to clients throughout the assessment. This may be support for anxiety and emotions, or to discuss more difficult topics such as sexual exploitation. Participants recommended that clinicians should give clients time to answer questions and allow for stalling in the assessment. Clinicians should check in with the client. Alexis stated:
 - ***“The things that I found were positive about the experience... taking time to hold a space at the beginning at the end to explore how I was feeling about the process”.***



3) Clinician Characteristics and Skills

3.3 Training of Wider Professionals

Another theme that emerged was the need for training in wider professionals (e.g., those not involved in the diagnostic process).

Participants described how teachers and educators are “*poorly trained*” on identifying autistic traits.

It was also stated that knowledge of sexual abuse in autistic females “*does not really exist in GPs in terms of their [Continued Professional Development] and their training*” (Harriet).

Discussion

- Overall, this study has highlighted the largely negative experiences of these autistic women during their diagnostic assessment.
- Recommendations to improve the experiences were made by autistic women, including the need for specialised training, changes/specialisation to the questions being asked, and awareness of the limitations of the diagnostic tools. A strength-based, compassionate approach is essential.
- It is hoped that assessing clinicians find these recommendations helpful in informing their practice and improving autism diagnostic assessments with women.

Guidelines to Assist in Autism Diagnostic Assessments with Females: A Delphi Study



Delphi Surveys - What is a Delphi study?



Goal - A Delphi study is a research method that uses a series of questionnaires to gather expert opinions on a specific topic.

Process - A panel of experts answer questionnaires, and their responses are summarized and presented to the group. The process is repeated for multiple rounds, allowing participants to reflect on and revise their opinions based on the group's responses

Key features - Anonymity, controlled feedback, iteration, and statistical aggregation of group responses

Benefits - Allows participants to reconsider their opinions based on others' responses, and prevents the authority of some participants from dominating the process

Design - Between March and June 2024, a three-round Delphi study was conducted among a panel of professionals with experience assessing females for autism in the UK.

Expert Panel

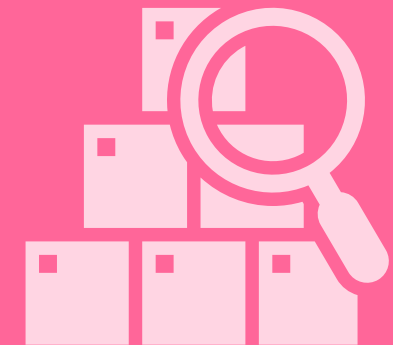
Participants were clinicians with experience diagnosing autism in females. In this study, an expert is defined as:

- Is a registered healthcare professional who has received appropriate training to conduct autism diagnostic assessments AND
- Has 12 months minimum experience of diagnosing autism through formal assessment AND
- Has assessed for and diagnosed autism in females AND
- Is practicing in the UK.

A sample size of at least thirty participants was sought, with a minimum number of 15

The study used a volunteer/snowball sample. The authors collated a list of clinicians based in the UK, who were either:

- known to practice within diagnostic services
- who has contributed to research on the topic



Expert Panel

- **34 participants volunteered and consented to participate in the Delphi. Of the 34:**
 - 24 completed Round 1 (67.6% retention rate)
 - 18 completed Round 2 (52.9% retention rate)
 - 16 completed Round 3 (47.1% retention rate).
- **Years of experience in autism diagnoses ranged from 2 years to 24 years, with a mean of 11.1 years of experience.**
- **The panel described completing autism assessments in the following settings: NHS outpatient services, private diagnostic services, inpatient settings including forensic inpatient settings, university clinics and local mental health teams.**
- **They assessed adults (N=21), children and young people (N=14) and individuals with intellectual disabilities (N=8).**
- **Clinicians reported that their knowledge of autism in females had developed through specialist autism courses, clinical training, independent research/reading, personal experience, and clinical supervision.**



Data Analysis



Round 1

Qualitative responses gathered in Round 1 were analysed using Sekayi and Kennedy's methodology, which involves coding and grouping statements.

Rounds 2 and 3

To examine consensus in Rounds 2 and 3, % agreement was calculated for each point on the scale.

Statements rated with "agree" or "strongly agree" by $\geq 80\%$ of participants were considered an integral component of diagnostic assessments in females.

Round 1 Questionnaire

Questions presenting in Round 1 were generated from the focus groups with autistic women and relevant literature producing open ended questions that related to five main categories:

- Assessment context
- Clinician attributes
- Assessment tools
- Questions asked during the assessment
- Sources of information



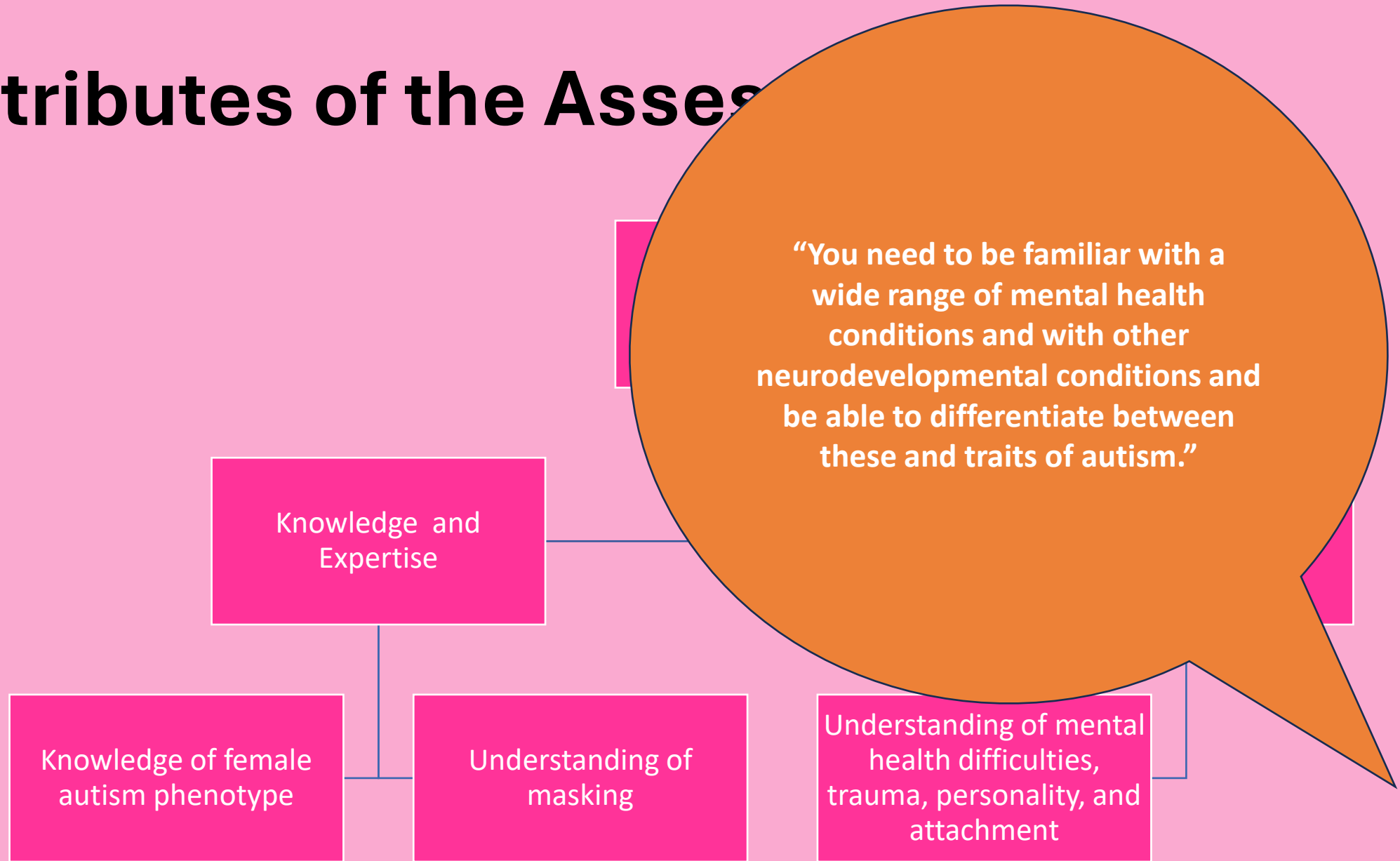
Results - Round 1

Thematic analysis identified five overarching themes:

1. **Attributes of the Assessor**
2. **Post-Clinical Qualification Education and Learning**
3. **Diagnostic Tools**
4. **Questions Asked**
5. **Sources of Information**

each with several subthemes.

Attributes of the Asses



Post-Clinical Qualification Education and Learning

“Ability to engage critically with the narratives around women and autism in the scientific literature and more broadly in societal narratives.”

“Subsequent CPD in female presentation, supervision around this.”

“Training from people with lived experience would be ideal”

“The most useful training is in shadowing experienced clinicians and multidisciplinary team discussions.”

Shadowing of Assessments

Diagnostic Tools

“Not a huge fan of the ADOS but it’s there if needed”

“I like to screen for autism (SRS-2 for example), masking (CAT-Q), other conditions such as OCD, ADHD, mental health difficulties and sensory sensitivities/differences”.

“Some tools are out of date, contain gender bias, or are designed for use with children, so they have to be used with caution and may need adapting”

Empathy

Questions Asked

“Quality of social relationships - both of friendships or intense relationships to maintain, using others to enjoy activities

“I ask lots of questions about a what form these take. It can be see if an interest is intense, so you impact of this, what form it takes, the etc. Most of the other standard questions females and males in my opinion - this is probably section that I modify least - although I do go in-depth about sensory issues as these can be subtle for females.”

“Questions around mirroring behaviours and repeating socially appropriate phrases in order to fit in, and superficial social communication used to mask a lack of understanding”

“I ask for lots of examples to help me better understand their experiences. I ask about the impact of these difficulties on different relationships and in different life domains (e.g. family, intimate, social, occupational, health)”

“There are some specific questions about menstrual cycle and ability to manage that as a younger person”

“Specific Prompts (e.g. periods, sex and menopause)”

Sources of Information

“To discuss complex cases, to check things out when unsure, to enhance knowledge and for support to guard against burnout.”

“Use of informants can differ among adult women. While parents are still spoke to, other informants appear to be considered as having utility within the process.”

Consensus Meetings

Approach

Assess for camouflaging

Results Rounds 2 and 3

| Item | Statement | Round 2 Consensus (%; n=18) | Round 3 Consensus (%; n=16) | Change in Consensus |
|---|---|-----------------------------------|-----------------------------------|------------------------|
| <i>Attributes of the Assessor</i> | | | | |
| 1 | A strong knowledge of the research field connected to the autism presentation in females is necessary | 100 | 100 | 0 |
| 2 | Clinical/psychological knowledge, particularly in regard to differential/comorbid diagnosis of psychological issues such as attachment, or other mental disorders, such as trauma and/or personality disorder is required | 100 | 100 | 0 |
| 3 | A strong knowledge of other developmental conditions is necessary | 100 | 100 | 0 |
| 4 | An awareness of masking is necessary | 100 | 100 | 0 |
| 5 | An awareness of the potential for male bias in the assessment tools used is required | 100 | 100 | 0 |
| <i>Post-Clinical Qualification Education and Learning</i> | | | | |
| 6 | Autism assessors must undertake their own reading of research/articles on autism within women and girls | 100 | 100 | 0 |
| 7 | Autism assessors must seek out CPD on autism in women and girls | 100 | 100 | 0 |
| 8 | Autism assessors must receive training from autistic women | 88.9 | 68.7 | -20.2 |
| 9 | New assessors need to shadow assessments of females | 94.4 | 93.7 | -0.7 |
| <i>Diagnostic Tools</i> | | | | |
| 10 | Screening measures (e.g., AQ-10, RAADS-14, AQ, EQ, CAST) can be useful for screening autism indicators in females | 83.3 | 93.7 | 10.04 |
| 11 | Care should be taken when interpreting screening tools due to the male bias that may be present | 100 | 100 | 0 |
| 12 | Screening measures are useful for providing narrative information, above and beyond the cut off scores | 88.9 | 87.5 | -1.4 |
| 13 | It is essential to use screening tools for differential diagnoses, such as ADHD, and depression, anxiety | 66.7 | 37.5 | -29.2 |
| 14 | It is essential to use screening tools for trauma/adverse childhood experiences as part of the assessment | 61.1 | 37.5 | -23.6 |
| 15 | It is important to use measures of empathy as part of the assessment | 55.6 | 18.7 | -36.9 |
| 16 | It is important to use measures of camouflaging when as part of the assessment | 83.3 | 68.7 | -14.6 |
| 17 | The ADOS-2 is not always helpful when assessing females | 77.7 | 87.5 | 9.8 |

Results Rounds 2 and 3

| Item | Statement | Round 2 Consensus (%; n=18) | Round 3 Consensus (%; n=16) | Change in Consensus |
|-------------------------------|--|-----------------------------------|-----------------------------------|------------------------|
| <i>Questions Asked</i> | | | | |
| 18 | More prompts/questions should be asked when assessing females to explore more subtle differences in social communication skills (e.g., about friendships, non-verbal communication) | 100 | 100 | 0 |
| 19 | More prompts/questions should be asked when assessing females to explore more subtle differences in restrictive and repetitive patterns of behaviours and interests (e.g., stimming, daily routines) | 100 | 100 | 0 |
| 20 | Questions about repetitive and intense interests should focus on the quality/intensity of the interest, rather than the topic itself | 100 | 100 | 0 |
| 21 | It is important to ask questions about masking, mimicking and mirroring others' behaviours | 100 | 100 | 0 |
| 22 | It is important to ask questions about experiences in different relationships (e.g., family, friends, colleagues) | 100 | 100 | 0 |
| 23 | It is important to ask questions about the experience of menstrual cycles, periods, and menopause | 77.8 | 68.7 | -9.1 |
| 24 | It is important to ask questions about experiences of sexual relationships (e.g., consent, intimacy, vulnerability) | 66.7 | 68.7 | 2.0 |
| <i>Sources of Information</i> | | | | |
| 25 | Multiple informants and sources from different areas of an individual's life and from different time-points in their life should be used | 83.3 | 62.5 | -20.8 |
| 26 | It is important to consider the possibility of masking when interpreting information from informants | 100 | 100 | 0 |
| 27 | Multi-disciplinary meetings, supervision and consensus are essential to making the diagnosis of autism in females | 77.7 | 56.2 | -21.5 |
| 28 | Multi-disciplinary discussions should be used to discuss the possibility of masking/camouflaging during the assessment | 83.3 | 62.5 | -20.8 |

Statements That Met Consensus (80%+)

Attributes of the Assessor:

- A strong knowledge of the research field connected to the autism presentation in females is necessary
- Clinical/psychological knowledge, particularly in regard to differential/comorbid diagnosis of psychological issues such as attachment, or other mental disorders, such as trauma and/or personality disorder is required
- A strong knowledge of other developmental conditions is necessary
- An awareness of masking is necessary
- An awareness of the potential for male bias in the assessment tools used is required

Post-Qualification Education and Learning

- Autism assessors must undertake their own reading of research/articles on autism within women and girls
- Autism assessors must seek out CPD on autism in women and girls
- New assessors need to shadow assessments of females

Diagnostic Tools

- Screening measures (e.g., AQ-10, RAADS-14, AQ, EQ, CAST) can be useful for screening autism indicators in females
- Care should be taken when interpreting screening tools due to the male bias that may be present
- Screening measures are useful for providing narrative information, above and beyond the cut off scores
- The ADOS-2 is not always helpful when assessing females

Questions Asked

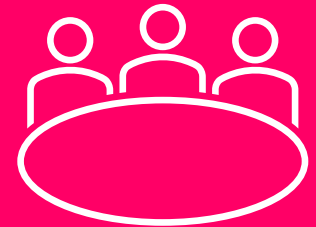
- More prompts/questions should be asked when assessing females to explore more subtle differences in social communication skills (e.g., about friendships, non-verbal communication)
- More prompts/questions should be asked when assessing females to explore more subtle differences in restrictive and repetitive patterns of behaviours and interests (e.g., stimming, daily routines)
- Questions about repetitive and intense interests should focus on the quality/intensity of the interest, rather than the topic itself
- It is important to ask questions about masking, mimicking and mirroring others' behaviours
- It is important to ask questions about experiences in different relationships (e.g., family, friends, colleagues)

Sources of Information

- It is important to consider the possibility of masking when interpreting information from informants

Discussion

- This Delphi highlighted inconsistencies in gender considerations within the diagnostic process between clinicians.
- There difficulties in accessing autism services, but also inconsistencies between services in the approach to diagnosis, and ultimately, the diagnostic outcome.
- This finding is of concern given the high levels of under-diagnosis highlighted by a recent population-based cohort study of primary care data. Research suggested people have an 85% chance of being diagnosed as autistic in some centres compared with a 35% chance in others (O’Nions et al., 2024)
- Barnard-Brak, Richman, and Almekdash estimated that 39% more girls should be diagnosed with autism than actually were, by comparing clinic and community-based data sets to national population estimates for sex distribution. Therefore, it is likely that autistic girls and women are one of the groups most affected by inequalities in access to, and outcomes from autism diagnostic assessments.



Discussion

- **Given the inconsistencies in practice highlighted by the Delphi and national data, it is evident that clinicians working within autism diagnostic services require guidance in the assessment of women and girls. This project aimed to take a step forward towards the development of such guidance.**
- **The next steps will be the development of guidance, which will combine the evidence base, perspectives of autistic women and girls, and the Delphi results. This guidance will build on the five themes highlighted within this research; Attributes of the Assessor, Post-Clinical Qualification Education and Learning, Diagnostic Tools, Questions Asked, and Sources of Information.**
- **The guidance will be the subject of wide consultation with a range of stakeholders to improve the experience and accuracy of diagnosis for girls and women undergoing autism assessment, increase consistency across services, and support assessing clinicians.**

Next steps - Task Force Needed for 2025: Guidelines to Assist in Autism Diagnostic Assessments of Females

- We are looking for autistic women, researchers, and clinicians who conduct autism assessments to contribute to this guidance.



Acknowledgements, questions and contact information

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|--------------------------|--|
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