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A hidden population? A qualitative and quantitative search for a female-phenotypic presentation of autism

Joshua Thomas Bailey Muggleton

THE UNIVERSITY of EDINBURGH

Doctorate in Clinical Psychology
University of Edinburgh
May 2017
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Title of Work: A hidden population? A qualitative and quantitative search for a female-phenotypic presentation of autism

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Signature .................................................................................................................. Date: April 21st, 2017
Abstract

Anecdotally, females with autism present differently from males. However, studies into autism tend to use a predominantly male sample, and make few gender-based comparisons. Hence, there is relatively little research on gender-specific presentations of autism. Furthermore, those studies that have been undertaken are equivocal in their findings. Should males and females with autism present differently, then the male preponderance in the research population may lead to a bias in our understanding of autism, and the diagnostic criteria it informs, creating circularity. This thesis aimed to investigate if and how females with autism present differently, while avoiding the problem of circularity.

As diagnostic criteria for autism consider behaviour (potentially biased to favour males), the diagnosed samples of participants in studies will present with similar behaviours, regardless of gender. However, gender differences may persist in areas of cognition, such as block design. A literature review of gender differences among people with autism on the block design task revealed only one adequately powered study; this indicated a possible gender difference. To expand the data available, a meta-analysis of studies comparing people with and without autism on the block design task was carried out. Then, the ratio of males and females within autism and control groups was regressed as a proxy indicator of gender differences. This did not reveal any gender differences.

An alternative approach was adopted within the research study. Through asking professionals highly experienced in diagnosing autism about gender differences in autism, it was hoped that they would express their own conception of autism, beyond the present diagnostic criteria, thereby avoiding circularity. A thematic analysis of interviews with 14 clinical psychologists with expertise in this area was conducted. Gender differences in presentation, but not underlying pathology, were noted by participants.
Trans-diagnostic constructs such as social awareness and motivation were thought to drive the gender differences in presentation. However, although the presentation and constructs were gender biased, they were not gender-specific, suggesting a broader view of autism is needed beyond dichotomous gender differences.
Anecdotally, females with autism present differently from males. However, studies into autism tend to use a predominantly male sample, and do not compare males and females to see if they perform differently. As such, there is little research on how males and females with autism present. The existing research that has compared males and females is sometimes contradictory or unclear. Yet, if males and females with autism present differently, then because more males with autism take part in research into autism, then our understanding of autism may only apply to males with autism, ignoring females. This could create circularity, as if only males are taking part in the research which informs the diagnostic criteria, then only males with autism will meet diagnostic criteria and get to take part in research. This study aimed to investigate if and how females with autism present differently, while avoiding the problem of circularity.

Diagnostic criteria are based on observing behaviour. However, cognition is largely ignored. Therefore, while people meeting diagnostic criteria for autism will have to have a male behavioural presentation (if there is a bias in the diagnostic criteria), they may still show differences in cognition. Research into gender differences in cognition in autism using the Block Design Task was reviewed. While one study indicated there may be a gender difference, the lack of research in this area meant more data was needed. To try to get around this problem, a meta-analysis of studies comparing people with and without autism on the block design task was carried out. Then, the ratio of males and females within autism and control groups was regressed as a proxy indicator of gender differences. This did not reveal any gender differences.

An alternative approach was used to assess if and how males and females with autism present differently. By asking professionals highly experienced in diagnosing autism about gender differences in autism, it was hoped that they would express their own conception of autism, beyond the present diagnostic criteria, thereby avoiding circularity. A thematic analysis of interviews with 14 clinical psychologists with expertise in this area was conducted. Gender differences in how people with autism present, but not in the underlying autism itself were described by participants. Participants described how
factors not directly related to autism, such as social awareness and motivation were thought to be behind the gender differences in presentation. However, although males and females presented differently, and these factors may be more common in males or females, they were not gender-specific. This suggests a broader view of autism is needed, and that it is not that males and females always present differently, but tend to have traits that lead to them often presenting differently.
Dedication

To my grandparents
Peter, Margaret, Bernard and Joyce
who taught me the value of hard work and perseverance
who taught me cooking and gardening, and kept me in woolly jumpers
and whose financial contributions made this possible
Thank you
Acknowledgements

This has simultaneously been one of the most exciting, exhausting and rewarding research projects I have undertaken, and it could not have happened without the support of many good friends, colleagues, and family members.

Thanks firstly to my supervisors, Ken MacMahon and Katrina Johnston. Both have gone above and beyond to help me make this project as good as it can be. Ken has provided excellent advice and guidance in crafting high-quality research, and in slowing my thought process down when I come to him, both when I’ve been overexcited like a small child with a new brainwave about my research, or panicking that something has gone horribly wrong. He has also provided superb advice on structuring my writing so that people other than me can understand it. Katrina helped me prune and nurture my initial research ideas into something possible and clinically relevant, contained my thesis related anxieties, and in the structure of my placements has ensured that I am always making links between my research ideas, theories and results, and my clinical practice, even when it means I ramble on at her about pieces of research I’ve found or ideas I have. Simultaneously, she has painstakingly read and re-read drafts for typos (, usually commas’ and, apostrophe’s) to a level of detail where I am quite certain she was previously employed as a professional editor.

Thanks are due to Tara Graham at NHS Fife who has always been on hand to help me navigate the bureaucracy that is ethics and NHS R+D. To Ethel Quayle and Angus MacBeth at the University of Edinburgh for guidance on the finer points of qualitative analysis and meta-regression. To Hollie Burnett for introducing me to Katrina, and listening to me when I go on and on about my thesis. Thanks again to Hollie, as well as Jess McCluskey and Laurie Siddell for reading early drafts and ensuring they are understandable to someone who has not regularly fallen asleep cuddling the latest issue of
The Journal of Autism and Developmental Disorders. Additional thanks to Laurie for being my independent rater for my systematic review, and for inventing Louis Tuesdays. Finally, thanks to Sarah Gillespie for being my sounding board for qualitative ideas and issues, and keeping me calm when it all seemed far too big!

I owe a huge note of thanks to the Edinburgh Doctorate in Clinical Psychology Class of 2017 for answering my numerous course-related Facebook posts and being generally the most awesome bunch of people I could ever have hoped to train with. Thanks also to Alex Szymanczak and Ali Warner, my best friends (even if they don’t believe psychology is a real science) whose magic facial hair trimming got me a place on the course, ensured I got settled into Edinburgh, and whose Sunday evening board games have provided a weekly diversion from work.

Thanks to my parents, John and Julia for their unwavering love and support. This is a milestone marking nine years of studying psychology which I would never have started, let alone continued without them. Special thanks also to my grandparents, Peter, Margaret, Bernard and Joyce, who helped to instil in me the values of hard work, of doing what you think is right despite what others might think, and who gave me the funds to pursue my passion.

Finally, my biggest thanks are undoubtedly to Serena Ashforth. I was once told that writing a thesis is like having a baby, or being in a (rather controlling) relationship. Quite how Serena has put up with over two years of my baby-mistress of a thesis making increasingly large demands on my time and brain space I do not know. She has supported me through stress, sleep deprivation and caffeine crashes with patience and good humour. She has ensured I have a rich and rewarding life outside my thesis, encouraged me to try new things (even if Oblivion and Saw still terrify me), and even got me running – something previously only achieved by bald, square-jawed, slightly scary P.E teachers. No matter how stressed I was, she has always ensured I
have a fun, relaxed, and thoroughly thesis-free time with her – the highlight of my week. Without her I would not have left my laptop, have a Vitamin D deficiency, and be snacking on Gold Blend instant coffee granules like they were popcorn. More importantly, without her, I would not be the person I am now, and neither would this thesis.

Thank you all
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A systematic review and meta-regression of gender differences in the Block Design Task in people with Autism

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As prepared for \textit{Autism: International Journal of Research and Practice}

For formatting guidance, see Appendix A1

5997 words
Abstract

Context: The Block Design Task (BDT) shows a small male bias in the Typically Developing (TD) population.

Objective: To investigate whether this effect persists in people with autism using a three-part strategy: (i) systematic review of studies using the BDT with people with autism; (ii) meta-analysis comparing people with autism to TD controls on the BDT; (iii) meta-regression, regressing the percentage difference in males between experimental and control groups against the standardized mean differences from part (ii) as a proxy indicator for the effect of gender on the BDT.

Data Sources: Medline (1946-2016), PsychInfo (1806-2016) and Embase (1974-2016) using search terms: (‘Autis*’ OR ‘ASD*’, OR ‘Asperger*’) AND (‘Block Design’ OR ‘Visuo-spatial’ OR Visuospatial) within title, keywords or abstract. Two related systematic reviews were also screened for relevant papers. Four-hundred-and-seventy-four studies were identified.

Study Selection: English language studies comparing people with autism by gender, or to TD controls on the BDT from a Wechsler battery were included. Studies including participants with schizophrenia or learning disabilities were excluded. Three studies remained for systematic review, and 12 for meta-regression.

Data Extraction: Data extracted by the lead author and evaluated using pre-defined inclusion/exclusion and quality criteria developed by all three authors.

Data Synthesis: Part (i) indicated a gender difference may exist, but a lack of research comparing males and females with autism led to minimal available evidence. Contrary to part (i), no significant effect was found in the meta-
regression, suggesting the characteristics of autism may 'over-ride' the effect of gender.

Conclusions: A paucity of research on gender differences on the BDT in people with autism limits our understanding about whether any gender differences exist. Further, limitations of using an indirect regression variable limit the confirmatory power of the meta regression. Further research on the influence of gender on cognition in people with autism is warranted.

**Key Words:** Autism, gender differences, block design, cognition
Introduction
Since its inception (Kanner, 1943; Asperger, 1944), autism has been more prevalent amongst males. Current estimates suggest a male bias (henceforth, referring to a bias favouring males) of 4.3:1 (Fombonne, 2003; Fombonne, 2005; Fombonne, 2007), dropping to 1.6:1 amongst people with autism and a learning disability (Volkmar, Szatmari and Sparrow, 1993). Skuse (2000) suggested that this discrepancy in prevalence may be due to a Female Protective Effect – that females are less likely to be impaired by autism, with supporting research (Gilman et al., 2011; Levy et al., 2011) with a large twin study suggesting greater genetic loading is required to manifest the autistic phenotype (Robinson et al., 2013).

However, it is possible any natural bias favouring males could become exaggerated within the research literature due to (by circumstance or by design) study samples consisting of more males than females. Watkins, Zimmerman and Poling (2014) found a male:female ratio of 6.07:1 in studies of people with autism, 40% higher than in the general population. Similarly, 17.79% of studies did not include any females with autism, with few of the remaining 82% comparing outcomes by gender (Watkins, Zimmernmann and Poling, 2014). This may lead research based diagnostic criteria to focus on a behavioural description of autism most common to males, neglecting (potentially) more feminine presentations, thus perpetuating the bias towards a male presentation.

There is limited research on gender differences in presentation of autism. Rivet and Matson (2011) note “relatively few” (p962) gender differences in autistic symptoms have been found, with many differing or non-significant results. However, the authors also noted a dearth of research in this area. Nonetheless, anecdotal reports of gender differences persist (Lai et al., 2015).
Mechanisms for gender differences in presentation

Autism, by definition, affects behaviour, cognition and perception. If it is assumed that females and males with autism are exposed to the same biological (e.g., genetics, hormones, brain development) and social (e.g., societal expectations, gender-stereotyped play, prejudices) influences on gender development as their TD counterparts, then the presence of autism could alter how social influences are perceived, how the person processes these biological and social influences, and how they react to them through their behaviour. This could be done in two ways.

First, autism may act as a moderator, enhancing, reducing, or altering the influence of some gender-defining influences. Here autism works as the conduit through which natural gender differences assert themselves. The second is that autism might ‘equalise’ the biological and social influences that are posited to result in the gender differences in behaviour, cognition and perception, thereby overriding and nullifying the effects of standard gender differences.

Breaking the circularity in diagnosis

Autism is a behaviourally defined condition. As such, there is a risk that common population-wide gender differences, and the interaction of these differences with autism or autism-specific gender differences, may impair the diagnosis of females with autism. Therefore, it is important that diagnostic criteria are adaptable to gender differences in autism. If not, this may risk an underdiagnosis of females, and perpetuate a gender bias in the research on which diagnostic criteria are based. Without establishing the validity of the diagnostic criteria across genders, comparing differences in symptoms (i.e behaviours) between genders in diagnosed people with autism is circular (see Figure 1.1), and unlikely to yield differences, as in Rivet and Matson (2011).
Behaviour is, in part, driven by cognition, meaning the differences in behaviour could imply differences in cognition. Supporting this, differences in cognition/cognitive strategies between genders have been observed in the TD population (Coluccia and Louise, 2004). Therefore, using cognition presents an opportunity to bypass some of the circularity of investigating gender differences in the behaviour of people diagnosed based on their behaviour.

**Current investigation**
One way to investigate gender differences in cognition is using neuropsychological assessments. The Block Design Test (BDT) from the Wechsler Intelligence Scales (Wechsler 2004, Wechsler 2008) is one such test that has been used extensively in autism research (Muth, Honekopp and Falter, 2014). The BDT is marketed as, and has been found to be, an effective test of visual spatial ability (Wechsler, 2008; Groth-Marnat and Teal, 2000). However, being a visual task, the BDT is susceptible to confounding through difficulties in visual sensation or perception. Further, difficulties with
fine motor skills, processing speed, and attention may lead participants to take longer to complete the tasks, confounding results.

A meta-analysis by Muth, Honekopp and Falter (2014) found that people with autism have a slight (d=0.22-0.32) advantage on the BDT, compared to controls. Shah and Frith (1993) found that while people with autism outperform TD controls on the BDT, this effect disappears when the pattern to be contracted is presented in pre-segmented form. This could be explained by the Weak Central Coherence theory of autism (Frith, 1989), which argues people with autism have a greater ability to see the parts of a whole, but struggle to see the whole itself. Therefore, in the BDT, people with autism may be quicker to segment the pattern to be constructed into their constituent blocks and thus are faster at completing the task. The Weak Central Coherence Theory does not suggest males and females with autism should have different levels of central coherence.

In comparison, the Extreme Male Brain theory of Autism (Baron-Cohen, 2002) suggests that TD males, will tend to outperform TD females on systemising tasks – the analysis or construction of rule based constructs, which the BDT could be argued to be. However this theory argues people with autism have an extreme male brain, and therefore would show greater ability in the BDT compared to TD controls. The theory and research supporting it, however, is unclear as to whether females with autism show an equally male brain to males with autism. Therefore, the theory is equivocal on whether a gender difference in the BDT could persist, be equalised, or be exaggerated in people with autism.

It is notable, however, that the Block Design Test is known to have a slight but significant male bias in the general population (d=0.34, based on a sample of 1368; Colom et al., 2002), comparable to the advantage found in people with autism over TD controls by Muth, Honekopp and Falter (2014). However, ~80% of the participants in this study were male. Therefore, a male
advantage on the BDT in people with autism similar to that in the TD sample could account for some or all of this effect.

These three competing theoretical arguments lead to three possible outcomes when considering gender and autism regarding the BDT: (i) the presence of autism negates any gender difference on the BDT; (ii) gender differences exist, but are altered by the presence of autism; (iii) population-based gender differences are unaffected by autism. All are possible and theoretically important outcomes.

This paper investigates gender differences in BDT performance in people with autism in two ways.

(i) A systematic review of studies comparing the performance of males and females with autism on the BDT. A meta-regression. By first conducting meta-analysis of studies comparing people with autism to a TD sample on the BDT, it is then possible to regress difference in percentage of males between the control and experimental participants against the standardized mean differences derived in the meta-analysis. In this way, the regression may detect if some of the effect size in studies is due to a male biased sample and male advantage on the task.

Literature Search
The following electronic databases were searched using Ovid: Medline (1946-2016), PsychInfo (1806-2016) and Embase (1974-2016). The search was carried out in November 2015 and repeated in February 2017. Overall, 802 studies with the terms (‘Autis*’ OR ‘ASD*’, OR ‘Asperger*’) AND (‘Block Design’ OR ‘Visuo-spatial’ OR Visuospatial) within their title, keywords, or abstract were found (see Figure 1.2). Additional papers were identified and included from an existing meta-analysis (Muth, Honekopp and Falter, 2014),
and a search by Stevenson and Gernsbacher (2013). Papers were screened against the following inclusion criteria:

- English Language
- BDT Scaled Scores reported
- Participants had autism
- Number of males and females in each group were reported
- Comparisons of gender, or to a TD control group

Studies that included participants with intellectual disabilities were excluded. People with intellectual disabilities are defined by the ICD-10 (1992) as having an IQ below 70, with corresponding impairments in adaptive functioning. As the BDT is part of the Wechsler Intelligence batteries, people with a learning disability will, by definition, be expected to score significantly lower on the BDT. Therefore, although autism and intellectual disabilities frequently co-occur (Fombonne, 1999) these were excluded from our study.

While other common comorbid conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) may impact performance on the BDT, it was felt that their effects on the BDT were sufficiently mild (see Mayes and Calhoon, 2006), and their comorbidity so widespread (28.2% for ADHD, Simonoff et al., 2008) that it would not be practical or ecologically valid to exclude these conditions. The exception to this was Schizophrenia, which was felt to be sufficiently uncommon in this population to warrant exclusion (Leyfer et al., 2006)

A review protocol was not pre-registered. Data was extracted by the first author.
Figure 1.2: Flowchart of literature

1. Papers identified from Medline, PsychInfo and Embase: N=802
3. Papers identified from Stevenson and Gernsbacher (2013): N=38
4. 1 inaccessible: N=22
5. 4 inaccessible: N=34
6. 384 duplicates removed: N=474
7. Screening for relevance: N=104
8. Excluded: N=370
9. Full text articles sourced: N=95
10. Full text inaccessible: N=9
11. Full text articles screened for eligibility: N=28
12. Articles identified as comparing male and female participants with autism on the BDT: N=13
13. Articles identified as comparing people with autism with controls on the BDT, with information on gender makeup of groups: N=16
14. Excluded: N=10
   Lack of data (n=1)
   Not conducting BDT gender comparison (n=9)
15. Excluded: N=4
   Lack of data (n=4)
16. Systematic Review Dataset: N=3
17. Articles identified as comparing people with autism with controls on the BDT, with information on gender makeup of groups: N=16
18. Excluded: N=4
   Not using Wechsler BDT
   Including participants with intellectual disabilities or schizophrenia (n=12)
   Not including participants with autism (n=3)
   Study does not report gender balance and/or has an inappropriate control group (n=9)
19. Meta-Analysis Dataset: N=12
20. Not English language (n=10)
21. Not conducting BDT gender comparison (n=9)
The remaining articles were separated according to whether they compared males and females with autism on the BDT (for systematic review, n=13), or compared people with autism to controls on the BDT (for meta-analysis and meta-regression, n=16).

Of those considered for the systematic review, one study was excluded for lack of relevant data, and nine for not conducting a statistical comparison of genders on the BDT, or failing to provide the information required to do this. These three remaining papers (see Table 1.1) were then evaluated against quality criteria (see Table 1.2). All three of these papers were identified by the original search. Where possible, post-hoc analyses were conducted to calculate achieved power using G-Power, using a one-tailed t-test model (reported in Table 1.1). Computing power based on the effect size achieved in the study is circular (Valentine, Higott and Rothstein, 2010). Therefore, an effect size of 0.32, based on Colom et al. (2002), was assumed.

**Quality criteria**

*A priori* quality criteria were created by the lead author (Appendix 1B). The criteria were derived with the aim of ensuring the validity of any gender comparisons made using the BDT, such as that an appropriate sample was used, and that the assumptions of statistical tests were met. The criteria were bespoke, created using a template (itself created by Paul Morris at the University of Edinburgh) by the first author, and reviewed, modified and agreed by all authors. The criteria were applied by the lead author and an independent rater (Table 1.2). Initial reliability was poor (Kappa=0.475), with most discrepancies between “well covered” and “adequately covered”. All discrepancies were discussed in person resolved according to strict interpretation of the criteria, resulting with 100% agreement.
Table 1.1: Summary of studies in the systematic review

<table>
<thead>
<tr>
<th>Study</th>
<th>Group</th>
<th>N</th>
<th>Age (s.d)</th>
<th>IQ (s.d)</th>
<th>Diagnoses</th>
<th>Diagnosis Verification</th>
<th>Exclusion Criteria</th>
<th>IQ measure</th>
<th>Effect size (d)</th>
<th>Power (d= 0.32)</th>
<th>Confounds</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bolte et al. (2011) Germany</td>
<td>Male</td>
<td>35</td>
<td>14.0 (3.0)</td>
<td>99.8a (11.3)</td>
<td>AU, AS, PDD-NOS</td>
<td>Consensus by five psychiatrists and psychologists. Met cut-offs on ADOS</td>
<td>IQ below 70, Lack of testability, lack of language, organic health problems</td>
<td>WISC-II, WAIS-R, or Raven's Progressive Matrices. (All Performance IQ)</td>
<td>0.268</td>
<td>0.207</td>
<td>5F and 6M on medication M and F scored significantly differently on ADOS stereotypic behaviour Reports significant interaction between subscales and gender, with M score higher than F on BDT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>21</td>
<td>14.3 (2.7)</td>
<td>98.6a (9.8)</td>
<td>As above</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dennis et al. (1999) Canada</td>
<td>Male</td>
<td>7</td>
<td>9.9 (6.1)</td>
<td>96.4 (24.5)</td>
<td>AU, AS</td>
<td>Confirmed by psychiatrist after interview and CARS</td>
<td>IQ below 70</td>
<td>WISC-III or WISC-R (Full Scale IQ)</td>
<td>N/Ab</td>
<td>N/Ab</td>
<td>Small sample size Only one F MANOVA on comprehension and BDT showed significant interaction with gender, but included other disorders.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>1</td>
<td>Amal</td>
<td>Amal</td>
<td>Amal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Koyama et al. (2009) Japan</td>
<td>Male</td>
<td>116</td>
<td>9 (3)</td>
<td>97.9 (13.6)</td>
<td>AU, AS, PPD-NOS</td>
<td>Consensus of multidisciplinary clinical team. Based on examination, observations, parent interviews, and developmental history.</td>
<td>IQ below 70</td>
<td>WISC-III, Japanese version (Full Scale IQ)</td>
<td>0.591</td>
<td>0.310</td>
<td>Created own definition for PDD-NOS. 11.4% - 15.3% scoring below cut off on CARS-TV Boys score higher on BDT, compared to girls, p=0.001</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>26</td>
<td>96.0 (14.2)</td>
<td>As above</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Amal = value amalgamated between males and females, AU=Autism, AS=Asperger’s Syndrome, PDD-NOS=Pervasive Developmental Disorder Not Otherwise Specified. CARS=Childhood Autism Rating Scale, ADOS=Autism Diagnostic Observation Schedule, M=Male, F=Female

* Non-verbal IQ

* Not calculable due to group composition
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Balance</th>
<th>Exclusion of other conditions</th>
<th>Diagnosis validated</th>
<th>Homogenous groups</th>
<th>Male and female groups comparable</th>
<th>Achieved statistical power</th>
<th>Appropriate statistical analysis</th>
<th>Appropriate reporting of statistical analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bolte et al. (2011) Germany</td>
<td>Adequately addressed</td>
<td>Well covered</td>
<td>Well covered</td>
<td>Well covered</td>
<td>Poorly addressed</td>
<td></td>
<td>Well covered</td>
<td>Well covered</td>
</tr>
<tr>
<td>Dennis et al. (1999) Canada</td>
<td>Poorly addressed</td>
<td>Adequately addressed</td>
<td>Adequately addressed</td>
<td>Adequately addressed</td>
<td>Not addressed</td>
<td></td>
<td>Adequately addressed</td>
<td>Well covered</td>
</tr>
<tr>
<td>Koyama et al. (2009) Japan</td>
<td>Poorly addressed</td>
<td>Adequately addressed</td>
<td>Well covered</td>
<td>Well covered</td>
<td>Poorly addressed</td>
<td></td>
<td>Well covered</td>
<td>Well covered</td>
</tr>
</tbody>
</table>
Of those considered for the meta-analysis and meta-regression, four studies were excluded for lack of data, leaving 12. Of these, eight were identified from the original search, three were identified from Muth, Honekopp and Falter (2014), and one from another paper. Investigation found these four studies were missed through their use of keywords not related to Block Design (such as ‘figure disembedding’).

**Part one: systematic review**

*Results*

Two papers aimed to investigate gender differences in cognition in people with autism. These were the only studies to address all elements of the quality criteria, usually effectively. All studies suffered from a male biased sample, but the severity of this bias ranged from adequate for statistical analysis, to insufficient to produce meaningful gender comparison.

Dennis et al. (1999) found people with autism score higher on the BDT than controls with Phenylketonuria or frontal head injuries. Gender was found to have a significant interactive effect on subtest scores on the WISC-III or WISC-R ($F_{1,30}=5.29$, $p=0.0291$), with males scoring higher on BDT than females. However, this effect was based on data from all participants, including those with Phenylketonuria or head injuries. As only one of the sample of eight people with autism was female, this is poor evidence of a gender bias in those with autism on the BDT.

Koyama et al. (2009) used a thorough screening for ASD and a large data set. While they used their own diagnostic criteria for Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), a clear and reasonable rationale for this is given and was combined with a robust detailed multi-disciplinary assessment requiring consensus. However, 11.4% of high functioning boys and 15.3% of high functioning girls with autism did not meet the clinical cut off on the Childhood Autism Rating Scale – Tokyo Version (CARS-TV; Tachimori et al. 2003). This is in line with the sensitivity
of the CARS-TV (0.86, indicating a 14% false negative rate; Tachimori et al., 2003) suggesting that the CARS-TV may not be sensitive to more mildly affected or unusual presentations. The risk of including participants without autism was, however, mitigated through the rigorous assessment process. Additionally, the size and similarity in proportion of genders not meeting the CARS-TV cut off, means any subsequent 'noise' would be unlikely to confound the studied effect. While the study was underpowered to detect the predicted effect size, they found an effect size greater than in the general population. This was statistically significant, with boys scoring higher than girls.

Bolte et al. (2011) attempt to establish whether gender differences in people with autism exist within attention to detail and executive functioning tests. The authors take care to ensure an accurate diagnosis according to the diagnostic criteria, and exclude some potential confounders. While their male and female groups are closely matched in size, they remain unbalanced. A significant interaction was found between sex and type of test. However, this was not significant when comparing genders on the BDT alone. This suggests that while there may be some gender differences in cognitive functioning in people with autism, any gender difference in the BDT was either non-existent, or too small for the study to detect (power calculated from presented data =0.397)

**Summary**

Of the three papers meeting criteria, only two were able to provide any results relevant to the review question. Further, studies tended to lack appropriate power and gender balance.

**Interpretation**

Koyama et al. (2009) indicate a gender bias, favouring males on the BDT. In contrast, Bolte et al. (2011) suggest that while there may be gender differences in executive function, there is no significant effect within the BDT.
Given Bolte et al.’s low power, an effect size equal to that of Koyama et al. would not be reliably detected. Therefore, the effect size found by Koyama could be an accurate estimate of the gender difference seen in the population, although further data are needed to support this.

Should the gender difference seen in Koyama et al. (2009) exist on a population basis, this would suggest that autism has an influence on gender differences. Koyama et al.’s finding of an effect size of 0.591 favouring males with autism over females with autism is significantly greater than the d=0.32 Colom et al. (2002) found for the general population. This could be through strengthening BDT ability in males and weakening it in females, or strengthening male ability more so than that of females. Although, any inferences drawn from a single study should be treated with caution.

The Weak Central Coherence theory of Autism (Frith, 1989) makes no claims of gender difference in its mechanism of action, and therefore cannot account for gender differences in people with autism on a task where weak central coherence has been shown to benefit people with autism (Shah and Frith, 1992). These results are, however, consistent with the Extreme Male Brain theory of Autism (Baron-Cohen, 2002), as the BDT is a systemising task. However, it should be noted that while consistent, these results would not be predicted by the Extreme Male Brain theory. The research underpinning this theory has yet to specify whether males and females with autism are equally effected by an ‘extreme male brain’. It may be that both males and females with autism have extreme male brains, which would then be inconsistent with this theory.
Part two: Meta-analysis and meta-regression

Introduction

The results of part one indicate that while a gender difference in BDT scores may exist in people with autism, there are insufficient data to support this conclusion. This is due to a tendency for existing research to be underpowered and not routinely compare genders in their analysis. However, it may be possible to increase the data available through using meta-regression. Like a meta-analysis, a meta-regression compares data from many studies, using their standardized mean difference, sampling variance and sample size to calculate whether the studies indicate a significant effect size. However, a meta-regression extends this process by using an extra variable to regress against the standardized mean difference.

A meta-analysis using papers comparing people with autism to TD controls on the BDT was conducted. This provided the effect size, sample size and sampling variance required for a meta-regression, whilst replicating (with more stringent inclusion and exclusion criteria) a previous meta-analysis by Muth, Honekopp and Falter (2014). The gender make-up of both the experimental and control groups were extracted from the studies. The percentage difference in males in the experimental and control groups was then used as a regression variable in the meta-regression.

Should a significant regression model be found, the following can be observed:

(i) The regression coefficient (the value to which x is multiplied to derive y) will define any relationship between the gender regression variable (i.e. difference in males between experimental and control groups) and any advantage the experimental (autism) group have over the control group. In this way, the regression variable, in part, captures any gender difference in the group with autism. In particular:
a. A positive regression coefficient indicates a stronger male advantage, regardless of group. This would imply the same gender difference is likely to exist in the group with autism.
b. A negative regression would indicate a female advantage.
c. The absence of a significant regression would suggest that there are no gender differences, or that gender differences differ between the control group and the group with autism.

(ii) The constant in the regression equation (the value added to the regression coefficient) will indicate the percentage of males fewer or extra needed in the group with autism to achieve the same scores as the control group, i.e. a constant of -10 would indicate that to equal the scores of a control group with 50% males, a group of people with autism would only need 40% males in their group. As such, this can be seen as a measure of any advantage conferred by an autism diagnosis.

A positive regression coefficient (male advantage, regardless of group advantage) combined with a negative constant (advantage for people with autism) was predicted.

Papers excluded from Muth, Honekopp and Falter (2014)
Muth, Honekopp and Falter conducted a similar meta-analysis in 2014. The current study’s search criteria were similar to their review, excepting the use of search terms relating to tasks not of interest (i.e. “mental rotation”) and a requirement for scaled scores for the BDT to be reported. In total, 13 papers were excluded from Muth, Honekopp and Falter’s (2014) original dataset of 23, most commonly for not using a BDT task from a Wechsler test, or poorly controlled or derived sample groups. A summary of these can be seen in Appendix 1C.
Method (meta-analysis and meta-regression)

Data extraction. Three studies reported multiple experimental (autism) groups being compared to a single control group. The meta-analysis assumed that data from each study was independent, meaning only one comparison could be made per control group. In these cases, the most relevant experimental group was used. As the BDT is a performance task, the experimental group with the closest Performance IQ to the control group was deemed the most relevant. In four studies where Performance IQ was not reported, Full Scale IQ was used.

Analysis
The standardized mean difference (d) was calculated as the primary outcome variable, with positive results indicating superior performance within participants with autism. Sampling variance was calculated using unbiased estimates. The meta-analysis was conducted using a random effects model.

The following meta-regression explored whether the gender makeup of the control and experimental groups affected the study results. The difference in percentage of males between the control and experimental groups was calculated and entered as a regression variable, using a mixed effects model. The analysis was carried out using R (R Core team, 2015) and Metafor (Viechtbauer 2010; Appendix 1D).

Results (meta-analysis)
306 people with autism and 331 TD controls over 12 studies were included in the meta-analysis (Table 1.3). The estimated population effect size was d=0.180 (p=0.0531, 95% CI: -0.0024 – 0.362, see Figure 1.3). Heterogeneity between the studies was not significant (Q(df=11)=14.816, p=0.191, tau=0.14), accounting for 19.85% of the variance. A funnel plot (Figure 1.4) indicated the possibility of publication bias, confirmed with Egger’s test (z=2.187, p=0.029).
Figure 1.3: Forest plot of meta-analysis results showing effect size and confidence intervals for each study

<table>
<thead>
<tr>
<th>Study name and year</th>
<th>Effect size and 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rumsey and Hamburger (1988)</td>
<td>0.59 [-0.31, 1.49]</td>
</tr>
<tr>
<td>Smalley and Asarnow (1990)</td>
<td>0.45 [-0.49, 1.39]</td>
</tr>
<tr>
<td>Ozonoff, Pennington and Rogers (1991)</td>
<td>0.15 [-0.45, 0.75]</td>
</tr>
<tr>
<td>Morgan et al (2003)</td>
<td>0.74 [ 0.11, 1.37]</td>
</tr>
<tr>
<td>Edgin and Pennington (2005)</td>
<td>-0.06 [-0.58, 0.47]</td>
</tr>
<tr>
<td>Williams, Goldstein and Minshew (2006)</td>
<td>0.14 [-0.23, 0.52]</td>
</tr>
<tr>
<td>Bolte et al (2007)</td>
<td>0.24 [-0.48, 0.96]</td>
</tr>
<tr>
<td>Ishida et al (2009)</td>
<td>1.14 [ 0.13, 2.16]</td>
</tr>
<tr>
<td>Holdnack et al (2011) (AS Group)</td>
<td>-0.31 [-0.79, 0.18]</td>
</tr>
<tr>
<td>Spek et al (2011) (AS Group)</td>
<td>-0.12 [-0.55, 0.31]</td>
</tr>
<tr>
<td>Bolte et al (2011)</td>
<td>0.24 [-0.13, 0.61]</td>
</tr>
<tr>
<td>Planche and Lemonnier (2012) (HFA Group)</td>
<td>0.45 [-0.28, 1.17]</td>
</tr>
<tr>
<td>RE Model</td>
<td>0.18 [ 0.00, 0.36]</td>
</tr>
</tbody>
</table>

Standardized Mean Difference

-1.00  0.00  1.00  2.00  3.00
Figure 1.4: Funnel plot comparing standardised mean difference to standard error for studies included in the meta-analysis and meta-regression.
<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>% male</th>
<th>Gender regression variable</th>
<th>Age (years)</th>
<th>IQ</th>
<th>BDT Scores</th>
<th>d</th>
<th>Sampling Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rumsey and Hamburger (1988)</td>
<td>10</td>
<td>100%</td>
<td>0.0</td>
<td>26.4 (7.35)</td>
<td>103.9 (13.6)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>14.9 (3.2)</td>
<td>0.587</td>
<td>0.211</td>
</tr>
<tr>
<td>Smalley and Asarnow (1990)</td>
<td>10</td>
<td>100%</td>
<td>0.0</td>
<td>28.40 (4.86)</td>
<td>111.1 (10.4)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>13.2 (2.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ozonoff, Pennington and Rogers (1991)</td>
<td>9</td>
<td>100%</td>
<td>0.0</td>
<td>20.3</td>
<td>95.1 (13.5)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>11.8 (4.0)</td>
<td>0.454</td>
<td>0.229</td>
</tr>
<tr>
<td>Morgan et al. (2003)</td>
<td>23</td>
<td>91.3%</td>
<td>1.3</td>
<td>12.1 (3.2)</td>
<td>98.4 (18.1)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>10.0 (4.0)</td>
<td>0.146</td>
<td>0.094</td>
</tr>
<tr>
<td>Williams, Goldstein and Minshew (2006)</td>
<td>56</td>
<td>82.1%</td>
<td>12.5</td>
<td>11.4 (2.2)</td>
<td>102.1 (14.6)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>11.8 (3.6)</td>
<td>0.145</td>
<td>0.036</td>
</tr>
<tr>
<td>Bolte et al. (2007)</td>
<td>15</td>
<td>100%</td>
<td>0.0</td>
<td>25.8 (7.7)</td>
<td>100.1 (12.4)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>10.9 (2.9)</td>
<td>0.242</td>
<td>0.134</td>
</tr>
<tr>
<td>Ishida et al. (2009)</td>
<td>9</td>
<td>100%</td>
<td>0.0</td>
<td>12.3 (2.0)</td>
<td>98.2 (14.1)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>13.6 (3.8)</td>
<td>1.141</td>
<td>0.268</td>
</tr>
<tr>
<td>Holdnack et al. (2011) (AS Group)</td>
<td>27</td>
<td>77.8%</td>
<td>-2.2</td>
<td>22.6 (7.6)</td>
<td>87.2 (12.1)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>9.7 (3.2)</td>
<td>-0.312</td>
<td>0.039</td>
</tr>
<tr>
<td>Spek et al. (2011) (AS Group)</td>
<td>41</td>
<td>90.2%</td>
<td>17.1</td>
<td>41.3 (11.9)</td>
<td>112.9 (14.8)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>12.6 (3.7)</td>
<td>-0.120</td>
<td>0.049</td>
</tr>
<tr>
<td>Bolte et al. (2011)</td>
<td>46</td>
<td>62.5%</td>
<td>22.8</td>
<td>14.1 (2.9)</td>
<td>99.4&lt;sup&gt;a,c&lt;/sup&gt;</td>
<td>11.6 (4.9)</td>
<td>0.239</td>
<td>0.035</td>
</tr>
<tr>
<td>Planche and Lemonnier (2012) (HFA Group)</td>
<td>15</td>
<td>93.3%</td>
<td>13.3</td>
<td>8.1</td>
<td>109.1 (13.5)</td>
<td>12.5 (2.4)</td>
<td>0.446</td>
<td>0.137</td>
</tr>
<tr>
<td>----------------------------------------</td>
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<td>--------</td>
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<td>-----</td>
<td>---------------</td>
<td>------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>80%</td>
<td></td>
<td>9.0</td>
<td>107.1 (9.0)</td>
<td>11.5 (1.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>306</td>
<td>81%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>331</td>
<td>73%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Results for the experimental group are reported above those of the control group. Mean scores are presented with standard deviations in brackets where available. a non-verbal IQ, b full scale IQ, c data extracted from Muth, Honekopp and Falter (2014), d Peabody Picture Vocabulary Test – Third Edition (PVT-III; Dunn and Dunn, 1997) Standard score
Results (meta-regression)

The difference in percentage of males between studies was entered as a regression variable. A small non-significant effect (d=0.005) was found (QM(df=1)=0.657, p=0.418), reducing the overall effect size to d=0.164. Heterogeneity and the effect of the model remained non-significant.

Figure 1.5 shows each study’s gender regression variable (positive scores indicate a higher percentage of males in the autism group, negative scores indicate a higher percentage of males in the control group), standardized mean difference (positive scores indicate an effect favouring the group with autism), and sampling variance (sampling variance has been inverted: studies with less variance display as larger ‘bubbles’). From observing the data this way, it is notable that there is no clear correlation: studies with less variance (larger bubbles) tend to fall into the first quadrant, indicating studies tended to have more males with autism and showed an advantage for this group. Further, studies with gender regression variables close to zero tend to align positively on the Y axis, indicating that even in studies with similar gender distribution in their groups, people with autism tended to perform better than TD controls.
Figure 1.5: Comparison of studies' gender makeup against standardised mean difference, weighted by sampling variance.
Discussion

Meta-analysis discussion

The current study found no significant difference (d=0.180, p=0.0531) between people with autism and TD controls on the BDT. In contrast, the meta-analysis by Muth, Honekopp and Falter (2014) found an effect size of d=0.32 (or d=0.22 after removing one extreme result), significant at the 5% level (p=0.012 and p=0.025 respectively).

This discrepancy may be due to differences in inclusion criteria. Muth, Honekopp and Falter noted a high degree of heterogeneity between studies in their analysis (tau=0.49). By using stricter exclusion criteria, the present study was able to reduce this variance (tau=0.14). This suggests one or more exclusion criteria encapsulated a confounding factor. Supporting this, studies that did not meet the stricter inclusion criteria of this meta-analysis tended to have more extreme results, both positive and negative. Appendix 1C indicates that within the range d=−3.5 to d=0.5, only two of 10 studies were excluded. However, beyond this range, 12 of 16 studies were excluded (although one was excluded due to language). This trend, although not reaching statistical significance, could imply that any differences between people with and without autism on the BDT are sensitive to the study design, type of task, and/or the characteristics of the participant. Therefore, there may be specific aspects of BDT-type tasks (such as speed, accuracy or type of stimulus) that favour people with autism, and vice versa.

Further research into how such factors influence performance may help identify the nature of any advantage autism confers, as well as whether any gender difference (within or between diagnostic groups) exists. For example, on mental rotation tasks, TD men and women employ different strategies, which, depending on the task demands and outcome variable, produce different results (Heil and Jansen-Osmann, 2008; Jordan et al. 2002; Alexander and Evardone, 2008). A similar difference could exist within those with autism on the BDT.
The current meta-analysis showed no significant effect, contrary to Muth, Honekopp and Falter (2014). However, the current study approached significance, with a 95% confidence interval encompassing both results from the previous paper. Therefore, this can be seen as a replication of Muth, Honekopp and Falter (2014), with the caveat that part of their effect size may be due to specific types of testing or measurement, rather than a general autistic advantage on the BDT.

**Meta-regression discussion**

The meta-regression attempted to identify whether gender differences had an effect on the advantage people with autism have on the BDT. Regressing the percentage differences of males between experimental and control groups had no significant effect on the model.

The lack of variance explained by the regression model suggests that the percentage difference in males between groups was not related to any difference in BDT scores between groups with autism and TD controls. Given that a gender difference does exist in the TD population on the BDT (Colom et al. 2002), this would suggest that this difference is not evident in those with autism. Given the advantage seen in studies involving people with autism on the BDT (such as part (ii), and Muth, Honekopp and Falter, 2014), this would suggest that autism may remove any gender difference on the BDT, giving males and females an equal advantage over the TD population. Alternatively, it may be that autism increases BDT ability in females, but not males. Further direct study of gender differences on the BDT in autism is required to identify what effect autism has on BDT in males and females, relative to their TD counterparts.

Nonetheless, in using an indirect measure, the meta-regression may not have been sensitive enough to detect any effect, given that any effect of gender would likely be small, relative to the noise in the data. Further, by
amalgamating the number of males and females in both experimental and control groups into a single variable, much of the variation with these data was lost. Thus, while the sample available to answering the question is increased, it is likely that only very large effect would be detectable through these means. It is unclear what a reliable alternative to this variable might be, as using two or four regression variables from these data will create collinearity, confounding the results.

**Summary**

This review sought to establish whether a gender difference exists in people with autism on the BDT. In part (i), a systematic review of the current literature on the topic identified only three studies. While the systematic review tentatively supported the possibility of a gender difference, favouring males, more data was required.

An indirect approach attempted to expand the data available. In part (ii), a meta-analysis of studies comparing BDT scores between people with and without autism was conducted, replicating Muth, Honekopp and Falter (2014). This failed to find a significant difference ($d=0.18$, $p=0.053$) between people with autism and TD controls.

In part (iii), using the model created in the meta-analysis, a meta-regression was conducted. This had little effect on the model. Given some effect would be expected from the effect found in the general population, this model may have lacked the sensitivity to detect any difference.

**Limitations**

Studying gender differences in cognition in those with autism means, by definition, only studying those whose behavioural phenotype matches that of the current behavioural diagnostic criteria of autism. If criteria are biased to a more masculine presentation, then the population studied could also be biased toward masculine behavioural presentations. This may mean that,
depending on the strength of the relationship between behaviour and cognition, there is insufficient variance within (this area of) cognition to detect gender differences. Thus, further research on gender differences within the Broader Autistic Phenotype (BAP) may be fruitful. Depending on the definition, investigating traits in those within the BAP, but not necessarily with a diagnosis of autism, may create sufficient variance for gender differences to be detected. Further, regressing the effect size of any gender difference with level of different autistic traits, may progress the debate on whether there is a meaningful clinical cut-off for autism and indicate which areas of impairment are affected by which areas of cognition.

The fundamental barrier to answering the core research question in this study was a lack of gender comparison in existing research. Of the 13 studies eligible for inclusion in the systematic review, nine were excluded for not reporting (or not presenting stratified data to allow) a gender comparison.

The lack of gender comparison suggests gender differences are not considered to be an important factor, despite gender differences on this task being seen in the TD population (i.e. the BDT, Colom et al. 2002). While this could be due to studies conducting, but not reporting, analysis into gender differences, results indicating the both presence of or lack of gender difference are meaningful.

Studies about autism may not routinely include gender analysis in the belief that gender differences in people with autism are unlikely (given theories such as ‘Extreme Male Brain’) or unimportant (given the assumption of male preponderance) and therefore not conduct gender analyses. However, evidence to support these assumptions is lacking. As such, opportunities for exploring gender differences in autism are routinely lost. Further, not conducting gender comparison, particularly when gender differences in the studied area are observed in the TD population, leaves the results from such analyses questionable.
Given males make up 81% of people with autism (4.3:1; Fombonne, 2003; Fombonne, 2005; Fombonne, 2007), recruiting sufficient females to power any gender comparison may be difficult, potentially leading to a tendency to use only/oversample males, perpetuating the bias. It could be argued that, as females make up only 19% of people with autism, studies using more than this could be over representing females (Edwards et al., 2012). However, this assumes that the gender balance in epidemiological studies is naturally occurring. Although this may be the case, it is also possible that the influence of clinician/societal expectations, lack of referrals or male-biased diagnostic criteria could lead to ‘typical’ females with ASD being ‘missed’, only recognizing those with a more masculine presentation. Regardless, if no gender differences exist, then overrepresentation of females would be unlikely to confound results, and thus would only hamper participant recruitment, not outcomes.

The recommendation of Watkins, Zimmermann and Poling (2014) that researchers should routinely report the gender composition of studies involving participants with autism is strongly agreed with. However, the current authors further recommend stratifying data by gender. Conducting tests of gender difference as a matter of course adds to both the reliability of the study and contributes to the debate on whether gender differences exist in people with autism.

Conclusion and future directions
This paper set out to explore whether gender differences in males and females with autism exist in the BDT. While a systematic review suggested, tentatively, a greater effect size than that seen in the general population, only two studies were of sufficient quality to contribute to this conclusion. The review also noted a paucity of research in this area, due to an absence of gender comparison within studies, as noted previously by Watkins, Zimmermann and Poling (2014).
A meta-regression attempted to add further data to the question. However, no evidence suggesting an effect of gender on BDT scores was found. Nonetheless, given the methodology it was necessary to employ, it is likely that only a large effect size would be detected. Therefore a gender difference in people with autism on the BDT still cannot be discounted. The by-product of the meta-regression was a meta-analysis, replicating Muth, Honekopp and Falter (2014), which compared people with autism to TD controls on the BDT. Unlike the earlier study, the current meta-analysis did not show an advantage to people with autism on completing the BDT. This was likely due to a reduction in heterogeneity between studies, attributable to stricter inclusion criteria. This may indicate people with autism are sensitive to the specific type of block design test employed, what is being measured, how groups are defined and the characteristics of these groups. Further research on gender differences in those with and without autism on variations of these tests may allow for common factors to be identified, elucidating gender differences in both this, and the general population.

This study also highlights, as a whole, a dearth of literature on gender differences in autism, and a failure of studies to report gender differences. Routine reporting of adequately powered tests of gender difference in studies of autism is important, as much research appears to rely on no clinically significant gender differences existing – an assumption as yet unproven. This will increase the validity of conclusions that are drawn, and reduce potential under-diagnosis of other autistic presentations, aiding our understanding of whether and where gender differences in this population exist. Understanding this will further our definition of autism, and enable exploration of the etiology of the disorder.
References


Exactly the same but completely different: A thematic analysis of highly experienced Clinical Psychologists’ conceptions of Autism in girls and boys

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Abstract
The preponderance of male participants in autism research risks creating a gender biased definition of autism, impairing research knowledge and clinical applicability. To bypass this potential circularity, 14 highly experienced Clinical Psychologists were interviewed about their conceptions of autism, and the gender differences therein. Thematic analysis revealed a complex picture. Autism was conceptualised by clinicians in a gender-neutral way based loosely on the triad of impairments with a focus on social interaction and communication. Girls and boys were thought equally affected by autism, but girls were viewed as likely to be more socially aware, more socially motivated, better at emotional recognition, and more internalising in their coping styles. Participants therefore thought girls tend to mask their difficulties, and present for assessment later. These autism-related gender differences may be influenced by gender differences in culture and biology. Culture also directly affects the environment of people with autism, and others’ perceptions of them. While girls may be more likely to present in a subtle way, boys can also present this way. Therefore, these differences should be framed in terms of trans-diagnostic constructs, rather than by gender alone.
Introduction
The Scottish Intercollegiate Guidelines Network (SIGN) recommend that, following identification, individuals suspected of autism are referred for specialist assessment (SIGN 145, 2016). Specifically, “A diagnostic assessment, alongside a profile of the individuals’ strengths and weaknesses, should be carried out by a multidisciplinary team which has the skills and experience to undertake the assessments” (p13). The assessment itself is recommended to contain both a detailed, autism focused developmental history, and a clinical assessment interview with the person being assessed. Further, the guideline recommends the use of clinical tools, such as Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter and Le Couteur, 1994), the Diagnostic Interview for Social Communication Disorders (DISCO; Leekam, et al., 2002), the Developmental, Dimensional and Diagnostic interview (3di; Skuse, et al., 2004), and the Autism Diagnostic Observation Schedule (ADOS; Lord et al, 2000) to assist in data gathering.

Throughout the guideline, SIGN (2016) reiterates the need for clinical experience in autism. This is because modern diagnostic criteria (DSM-5, 2013) attempt to describe diverse presentations of autism. As no underlying cause of autism has been established (despite repeated attempts; Baron-Cohen, Leslie, and Frith, 1985; Frith and Happe, 1994; Baron-Cohen, 2002), diagnostic criteria rely on the observation and classification of the effects of the condition: behaviour. However, heterogeneity in the severity, number, frequency and presentation of these behaviours makes defining autism particularly difficult. Diagnostic criteria therefore use subjective descriptors that rely on clinicians’ judgements to classify behaviour as sufficiently “abnormal” or “reduced” to meet diagnostic criteria.

All gender differences are subject to substantial individual differences and should not be generalised to all persons of any gender (an assumption made throughout this paper). However, broad gender differences in behaviour do exist (e.g. Archer, 2004; Baron-Cohen and Wheelwright, 2004; Hall and
Matsumoto, 2004). Wood and Eagly (2002) argue that gender differences in psychology are a result of a combination of biological and social influences. Given those with autism share a biology and social environment to their typically developing (TD) counterparts, anecdotal gender differences in the behavioural presentation of autism (Attwood, 2007; Kopp and Gillberg, 2011) are unsurprising. Such differences present difficulties in applying subjective diagnostic criteria:

1) **Accounting for normal gender differences in individuals with autism**
Clinicians must account for gender differences seen in the TD population during autism assessments. For example, as TD females tend to show greater ability to read non-verbal communication of emotion (Hall and Matsumoto, 2004), should less severe “deficits” in social communication, relative to males with autism, be sufficient for diagnosing females?

2) **Impact or impairment?**
If autism has a reduced impact on girls, then clinicians must decide whether the **impact of an impairment, or the impairment itself** is diagnostic. If, as the DSM-5 (2013) argues, the former is true, then our view of autism is one solely of the impact of impairments (defined by behaviour and social norms), as it disregards people who are impacted by autism but not impaired sufficiently for diagnosis. This limits our ability to investigate and understand autism.

3) **Gender biases in research underpinning diagnostic criteria**
Historically, males have substantially outnumbered females (e.g. Kanner, 1943; Asperger, 1944). Currently, estimates of the male:female ratio in autism are 4.3:1 (Fombonne, 2003; Fombonne, 2005; Fombonne, 2007). While there may be underlying bias towards males in the population (Attwood, 2006), the research into autism uses predominantly male participants, with few male/female comparisons (Watkins et al., 2013). If
research is based on a predominantly male sample, our understanding and definition of autism may only be valid for males. This could lead to fewer females being diagnosed, perpetuating the male preponderance (Figure 2.1).

**Figure 2.1: Theoretical cycle perpetuating masculine phenotypic presentation of autism.**

4) **Clinician biases in expectations**

Original descriptions of children with autism were heavily biased toward males (Kanner, 1943; Asperger 1944). While this bias may reflect underlying population ratios, it may have also influenced researcher and clinician expectations; namely that autism is a predominantly male condition. Consequently, clinicians may feel reluctant to consider an autism diagnosis for females, or feel ill prepared to assess females.

**Implications of gender bias in assessment**

A gender bias towards a masculine presentation may make it harder for those with a more feminine presentation (presumably mostly females, but could include males) to be diagnosed, and lead many with autism to go undiagnosed and unsupported. Supporting this, girls are significantly less
likely to meet diagnostic criteria than boys when presenting with the same number of autistic-like traits (Dworzynski et al., 2012; Russell et al., 2010). Equally, females are diagnosed with autism significantly later than males (Begeer et al., 2012; Giarelli et al., 2010). Therefore, given the value of early diagnosis and intervention (Koegel et al., 2014), assessment that is not equally valid for both genders risks discrimination and inequity of support for females with autism. Further, in only considering a masculine presentation, autism research will only have accessed part of the autism presentation, limiting its validity.

**Next steps**
Research examining if and how girls with autism present differently is required. Lai et al. (2015) suggest a framework for this. They propose a broad construct of autism free from gender differences, such as the DSM-5’s “persistent deficits in social communication and social interaction” and “restricted, repetitive patterns of behaviour, interests or activities” (RRBIs). Below this, narrow constructs of more “fine-grained subdomains, such as the DSM-5 symptom subdomains (e.g. social-emotional reciprocity)”, where gender differences could exist, with behavioural exemplars demonstrating the difficulties associated with autism, and the gender differences therein.

However, if females are systemically under diagnosed and underrepresented within the research, then our broad construct of autism may be biased. Therefore, research needs to revisit this broad construct to ensure a gender-neutral definition before narrow constructs and behavioural exemplars can be examined. Not doing so risks creating a masculine definition, with a ‘special case’ for females.

Given the risk of a gender bias in the existing research and diagnostic criteria, any investigation into the definition and presentation of autism will need to avoid the use of diagnostic criteria, or quantitative measurement of
pre-defined areas of impairment based on the current conception of autism, as this would create circularity. Therefore, a qualitative approach is required.

The current study
This study aimed to investigate gender differences in the conception and presentation of autism at the narrow constructs level, with behavioural exemplars. Supporting this, two secondary aims were included. First, to investigate clinicians' conceptions of the broad construct of autism for the reasons outlined above. Second, to understand how circularity in diagnosis may be prevented by investigating how gender differences present and are handled at diagnosis.

To allow for new behaviours and constructs to be identified, a qualitative approach was used. To create a homogeneous description, the focus was restricted to the presentation of children (<18 years), and one professional group: clinical psychologists.

Clinicians diagnosing autism will have been trained to do so using diagnostic criteria, diagnostic tools, and research, all of which are at risk of bias favouring. However, through experience, clinicians may have developed their own understanding of autism that goes beyond the diagnostic criteria. By interviewing clinicians highly experienced in diagnosing children with autism, the current study attempted to capture their conceptions using thematic analysis to produce a more ecologically valid understanding of what autism is, and what the gender differences are.

Methods
Recruitment
Participants were contacted indirectly, either through an invitation sent via the heads of child and family clinical psychology services in Scotland, or through the authors’ own contacts. The invitation included a study outline and an invitation to take part (Appendix 2A). The study aimed to recruit 14
Clinical Psychologists, based on Guest et al. (2006), with no more than two participants from any NHS Health Board to limit institutional bias. Sixteen Clinical Psychologists volunteered, in addition to several other health professionals. All authors reviewed experience summaries and recruited 12 Clinical Psychologists into the study. Participants were chosen by all three authors with the aim of creating an experienced, homogeneous sample. Overall, four participants were rejected, either for working in private practice (when the majority worked for the NHS), self-identifying as having limited experience, or having experience too similar to another participant meaning it would be unlikely they would be able to contribute new information. To reach 14 participants, an extra Clinical Psychologist was recruited from two Health Boards, both of which were already employing two participants. Both participants were approached by colleagues already taking part in the study. Other health professionals were not recruited to limit heterogeneity. While other professionals (specifically psychiatrists, paediatricians and Speech and Language Therapists) were considered, it was felt that due to the researchers’ backgrounds, Clinical Psychologists would be easiest to access, and have an understanding of autism most easily understood by the researchers.

Procedure
Participants were contacted with further information about the study and gave informed consent (Appendix 2B). Each participant was interviewed once at their work in a private room between April and August 2016. Participants were interviewed by JM for 60-90 minutes using a semi-structured interview schedule (Appendix 2C) focusing on what autism is, gender differences (or lack of) in autism impairment and presentation, and differences in diagnostic procedures. The interview schedule was created through discussion by all three authors, based on the anecdotal differences noted by Lai et al. (2015), and the researchers own understanding of autism, influenced by the Triad of Impairments as presented in the ICD-10 (WHO, 1992). No changes to the interview schedule were deemed necessary after
the first two (pilot) participants, which were included in the analysis. Interviews were recorded on a dictaphone and transcribed verbatim by JM. JM noted a high degree of cohesion between accounts during interviews, even when some participants held a particular theoretical viewpoint. On discussion and review of transcripts, all authors agreed that data saturation had likely been reached.

*Participants*

Participants were Clinical Psychologists in the NHS (see Table 2.1). Duration of experience was deemed a poor proxy for quality of experience. Similarly, recruiting only from highly specialist teams would limit the participant pool, increase the risk of institutional bias, and limit applicability of results. Therefore, participants’ self-identification as experienced with a strong conception of what autism is, was deemed sufficient for inclusion in the study.

**Table 2.1: Participant information**

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<td>Males:females</td>
<td>3:11</td>
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<tr>
<td>Scottish/English Health Board</td>
<td>9/5</td>
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<tr>
<td>Setting: General child and adolescent mental health services (CAMHS)</td>
<td>8*</td>
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<tr>
<td></td>
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<tr>
<td>Specialist assessment teams within CAMHS</td>
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<tr>
<td>Local highly specialist assessment services for autism</td>
<td>3*</td>
</tr>
<tr>
<td>Regional highly specialist assessment services for autism and other conditions</td>
<td>6*</td>
</tr>
<tr>
<td>Actively engaged in research</td>
<td>6</td>
</tr>
<tr>
<td>Retired/semi-retired</td>
<td>1</td>
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</tbody>
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\*non-exclusive field

*Researcher*

JM, 27, was the primary investigator who conducted the interviews and analysis. He was employed as a trainee Clinical Psychologist and has significant clinical and research experience of autism. He also has a
diagnosis of autism, and he has lectured on the subject for 12 years. He knew four of the participants professionally to varying degrees. This project was conceived out of JM’s curiosity in ‘pinning-down’ what autism is, and need to conduct a substantive piece of novel research for his clinical training.

Analytic procedure
Thematic analysis was conducted based on Braun and Clarke (2006). However, due to the richness of the data, it was not possible to generate an easily manageable number of codes. Therefore, a variation was adopted, using elements from thematic networks (Attridge-Stirling, 2001):

1) JM read each transcript while listening to the recording, making preliminary notes on context/tone. A line-by-line reading by JM was used to generate a brief descriptor for every point made (see Appendix 2D-2E). Both KM and KJ each analysed six sample pages of text with JM to ensure validity. In total, 2606 unique descriptors were generated.

2) Descriptors were iteratively hand sorted into progressively smaller semantic groups, reconfirming with the original text where needed. Three-hundred-and-eighty-six codes emerged, with KM and KJ reviewing samples of descriptors in their codes to ensure validity (Appendix 2F).

3) All authors reviewed all codes and their initial themes (created by JM) renaming themes, combining and deleting codes, and reviewing descriptors within codes where there was ambiguity. Seventy-one starter themes were generated which all authors agreed on (Appendix 2G).

4) One-hundred-and-forty-two hitherto miscellaneous descriptors were reviewed and placed within codes, generating 15 new codes in the process. The remaining 51 descriptors were reviewed by all three authors, who agreed they made a negligible contribution and could be discarded (Appendix 2H-2I).
5) JM arranged starter themes and their codes into groups, creating a hierarchical thematic structure, with additional links between different themes/codes to create a series of increasingly refined models that accurately described the content of the codes (Appendix 2J). These were reviewed by KM and KJ.

6) The number of descriptors in each code was checked, and a sample of original text contributing to each code was reviewed. Codes with less than six descriptors and with contributions from less than three people were marked as minor codes and highlighted in red. At the same time, five codes deemed to not contribute to the model were removed (Appendix 2K).

7) An interpretive model was created (Appendix 2L), with a more condensed version (Appendix 2M) used in this paper. Both models were agreed by all authors.

**Ethical Approval**
Ethical approval was granted by the University of Edinburgh (Appendix 2N-2P). The project was sponsored by the University of Edinburgh (Appendix 2Q), and approved by each Health Board’s Research and Development department (Appendix 2R).

**Analysis**
While all the data was analysed, due to the volume and complexity of data, a full report of the model is not possible within this paper. The current paper will provide an overview of the model, but focus on gender differences in narrow constructs and behavioural exemplars. Subsequent papers will explore aspects of the model in greater depth. All quotes use pseudonyms. Themes are referenced by their number (in brackets), and refer to their place within the thematic network found in Appendix 2M.
Overview

Participants’ accounts oscillated between two key themes. The first considered the presentation of boys and girls with autism (1), and illustrated how both genders share the same underlying impairments but the presentation of these impairments, and the difficulties boys and girls face, can be very different. The second discussed gender differences in the diagnosis of autism (2). While the diagnostic process was very similar for boys and girls, the presentation of girls, and therefore how the assessment is carried out, may be slightly different, and more challenging.

Three smaller themes link both larger themes. Theme three outlines participants’ conceptions of autism as based loosely on the triad of impairments. Theme four discusses the different diagnostic pathways for boys and girls with autism. Finally, theme five discusses the effects of culture on how autism is thought about, and on people with autism themselves.

Participants’ conceptions of autism

[Autism is] a social communication disorder affecting social interaction, communication and repetitive restricted stereotyped behaviours and restricted interests. […] I think it misses some things. […] for example, cognitive rigidity and emotional dysregulation and things like that, which don't quite feature in the criteria. […] I think it, it matches what we see, but I don't think it necessarily captures the whole picture.[Isabella;1-20]

As Isabella illustrates, even if not explicitly named, the triad of impairments is the basis for participants’ thinking about autism (3.4), was felt to be useful (3.4.2), and underpinned the diagnostic criteria (3.4.1). However, participants felt the triad did not capture “the whole picture”. Thus, their triadic conception was expanded and adapted to include other aspects of autism (3.2) and its development (3.6), such as motor clumsiness, emotional dysregulation, and executive functioning.
Participants’ expanded triadic conceptualisation of autism contained a core difficulty in social interaction and communication (3.1):

I probably to some degree hold onto the idea that there needs to be difficulties in both those areas, or all those areas, erm, but that there needs to be a core difficulty in social communication for me to consider autism. So we see quite a lot of kids in this clinic who will be quite rigid or may have very specific interests, but that that is obviously insufficient for autism. What I would be more willing to consider children that have quite big difficulties in social reciprocity, reciprocal interaction, even if they don't have the rigidity so much. [Jason; 12-20]

As Jason makes clear, this is not to disregard other aspects of autism, but that while other aspects may be common contributors to autism, they are ultimately optional, whereas a core difficulty in social interaction and communication is essential.

This tendency to relate autism back to this core difficulty is evident throughout participants’ descriptions. For example, seeing if a child understands and can relate socially is key in assessment, (2.3.1):

In that one to one situation, it exposed some of the real communication social interaction style difficulties [...] that is the core of this young person, that it is not about the trauma if that makes sense. Other things in terms of their behaviour, their awkwardness, their interaction with peers. [...] But it is again just thinking 'what is at the core of this young person?', and what can’t be explained if you like. [...] some things just felt 'this is who you are, you just don’t, you just don’t get this [Emma; 974-985].

Here, Emma explains how a sense of ‘you just don’t get this’ social communication and interaction being ‘at the core of this young person’ was key when assessing a young person. This is not to ignore the effects of RRBIs, but that there is something fundamental about this person’s lack of understanding that she is looking for to confirm or disprove autism.
Gender differences in autism

Participants felt that the underlying difficulties of autism were the same for boys and girls, as Katie illustrates:

*I’d say I’m looking for the bones [of autism]. So I am comparing them to the bones, and my understanding of the bones. So whether or not that is boys with autism or girls with autism.* [Katie;669-674]

*If the bones are there, I’d say, sort of typically, most girls and boys feel a bit different, but I’d say their bones are pretty much the same.* [Katie;99-100]

As such, although there was not universal agreement in all areas, most participants felt that boys and girls with autism had the same underlying level of ability (or impairment), including communicative ability (1.4.1), rigidity (1.5), imaginative ability (1.6.1), special interests (1.7.2), and social ability (1.8). However, while not part of participants’ conceptions of autism, on related abilities, such as social awareness (1.3.1), social drive (1.8.1), and emotional recognition and empathy (1.8.4), girls were thought more able.

Effects of social awareness and insight

While the underlying level of impairment due to autism may the same, participants found girls with autism appear more socially motivated, and more socially aware, as Grace and Emma illustrate:

*I think girls are also often appear to be more socially motivated [...] than boys, and kind of keen to have friends, and for whatever reason just can't, you know don't have the, necessarily have the social skills to actually... maintain those friendships.* [Grace;81-85]

*I think [girls with autism] are a bit better at [social awareness]. So, I think they can learn what they are supposed to do quite well. They know about saying "hi, how are you", that kind of social etiquette, the cues. [...] They know about eye contact, and they can model what they are supposed to be like. I think they pick up quite easily, they learn how they are supposed to be. Whereas I don't think boys have got that same awareness.* [Emma;408-416]
Given their increased social awareness, participants felt that girls were more likely to recognise they were different (1.3.2). As Emma intimates, due to their desire to have a social identity as part of a group of friends (1.3.3) girls want to remedy that difference. Girls therefore watch their peers, learn how they behave and interact, and then copy this behaviour, thereby masking their difficulties (1.3.2).

Participants explained how the process of observing, copying and learning from others’ behaviour, to compensate for a lack of understanding, means girls’ behaviour may not initially seem unusual, making them harder to identify. For example, girls’ imaginative play looks superficially better (1.6.1), and they may hide their special interest (1.7.1). Indeed, across areas that are investigated when assessing for autism, participants suggested that girls can mask their difficulties with superficial responses which, to a casual or inexperienced observer, may appear adequate but lack real understanding (2.3.1, 2.6.3), as Deborah explains:

*So I would do a standard assessment. I think you would have a bit of awareness that girls do, or can present differently [...] So when you are doing an [autism assessment], and you are asking questions around, you know, emotions and social understanding, I wouldn't just take the first answer, I would dig a bit below the surface to see if they, if they have not just learned it, if they actually have the real understanding of what they are saying. So I would try and tease it out a bit more.*[Deborah; 255-266]

**Effects of culture**

Participants felt culture (societies’ expectations of boys, girls, and autism) affected the presentation of girls with autism. Cultural expectations, such as ‘boys are boisterous, girls are empathetic’ were thought to impact on children themselves (as seen by their gender-stereotypical play; 1.6.2), and on their presentation of autism (5.2). For example, as TD girls’ play is more based on conversation, this was thought to provide girls with greater social skills training, as Emma explains:
For a lot of the kids that we see, and I feel like I'm completely playing into the gender stereotype society has set up, but I feel that's the way it is, the boys talk to me about playing tig or hide and seek and playing on the trampoline, whereas the girls, you know, it's about the chat if that makes sense? Which is why I wonder if they are able to learn the social skills a bit better, do you know, “hi, how are you?”, and the eye contact, they can do that, but the boys can't so much. So they, kind of, their difficulties are kind of masked a little bit. [Emma; 449-455]

Culture also influences our perceptions of autism. Participants felt that people saw autism as culturally acceptable for boys, but not for girls (5.3.1). This means that girls can have a diagnosis that is not accepted by those around them, leading to a relatively lower level of support, as Hannah explains:

I think because so many girls are missed, people are interacting with girls with autism as if they are not girls with autism, and I'm really conscious that sometimes we diagnose it but schools don't accept the diagnosis. People's friends don't necessarily accept it. Whereas with boys often it is just that bit more obvious, so it's more, once you've given that label, people respond to that child as if they are a child with autism. I think sometimes we give the label to girls and I think people think 'oh they are just shy'. [...] and therefore doesn't treat, don't treat them in a particularly different way. [Hannah; 241-249]

Further, even when diagnosis is accepted, participants felt people find the idea of a girl having autism incongruent, so either the diagnosis fades from consciousness, or the strategies they ably apply for boys with autism are not applied to girls, again potentially leading to a reduction in support (5.3).

Participants indicated that a side effect of this 'autism is for boys' stance is that people do not know how autism presents in girls (5.4). As such, participants found that autism is not considered for girls who are struggling (5.4.1), and when it is, some professionals can be reluctant to assess them (5.4.2), as Becky highlights with an example:
She was getting all these other labels, you know, she wasn't attending school, and she, oh she had all these physical diagnoses and I think people were, yeah, just. I don't know why they were so desperate to find another reason, I just, I think maybe it just doesn’t quite fit with peoples’ model of a girl, and that they can’t be on the spectrum, or you know, maybe they are really impaired kind of, learning disabled kids. That is, that is ok. But for the higher functioning ones, it just doesn't quite kind of, fit for people.[Becky; 649-657]

Effects of coping styles

Participants identified that girls and boys also differ in coping styles. Girls with autism tend to be more internalising than boys with autism, who tend to be more confrontational and externalising (1.1.5):

[…] one of the ideas would be that the kind of tendencies that are already there are may be slightly exaggerated to some degree. […] So in terms of mental health and other conditions, often you see boys or men externalizing more, while girls tend to internalize more. So one of the key things in terms of the differences between the male and female [autism] presentation is the trajectory. Boys maybe you see get diagnosed pretty early, even in the more subtle cases normally at the age of five, six when kids start school. There are behaviour problems brought to attention. While for girls, they may be more passive, less, more kind of, passive and slipping into the background and they don’t come to our attention until social demands increase by the time they are 14, 15 for example. [Jason;51-61]

As Jason highlights, internalising/externalising was thought of as an extension of a gender difference within the general population. Importantly, it was thought these differences in coping style may lead to gender differences in presentations of autism (1.2.1). Boys with autism tend to be identified for assessment due to their behaviour (4.3), a function of how they are coping with the difficulties the world presents them. Girls, however, due to their masking, are not spotted, and try to cope with the world and their autism without support (1.1.3). However, the demands on their coping are increased by the social-developmental jump (1.1.3), often surpassing their ability to
cope. Consequently, many girls are referred for diagnosis after contact with mental health services in their teenage years (4.3.1, 4.3.3).

**Effects of Biology**

So, it has been my impression, that girls can probably be, being female moderates against some of the social communication deficits. But it is just an open question as to why. [...] I think, where you've got a family group who, several siblings have got autism, or Asperger’s or some variant of social communication disorder, and they have had similar environments, and you know I've not been able to see parenting being differently to boys and girls, it feels like there is something that is to do with being female biologically that is mitigating against the expression of a social communication disorder. [Michael; 214-228]

While culture was seen as having a significant effect on gender differences in presentations of autism, participants acknowledged the effect of biology. As Michael explains, girls were thought to have some biological protection against autism, contributing to a subtler presentation (3.3). It is therefore not clear how much of the mechanism behind the differences in girls’ presentation discussed here (social awareness, social drive, and coping) are due to biology or culture.

**Discussion**

This study aimed to explore gender differences in the narrow constructs of autism, with secondary aims of exploring the broad conception of autism and gender differences in diagnosis, using thematic analysis. Participants’ understanding of autism was complex, with multiple links within and between themes of the conception, presentation, diagnosis, diagnostic routes, and the effects of culture on autism. There was minor disagreement in some areas, such as whether girls were more, less or equally affected by certain areas of autism, but a coherent consensus was clear.
The paper presents the results pertaining to gender differences in narrow constructs and behavioural exemplars. Results concerning to the broad construct of autism are briefly reported to contextualise the narrow constructs.

Broad construct of autism
Participants’ conception of autism was free from gender differences, and based on the triad of impairments seen in older diagnostic criteria (social interaction, social communication, and RRBIs; ICD-10, 1992; DSM-4, 1994), distinct from the original Wing and Gould (1979) triad of “social interaction, repetitive activities in the place of imaginative symbolic interest, and impairment of language development”. However, unlike either pre-existing triad, at the core of participants’ conceptions were deficits in social interaction and communication. The presence of these two constructs was seen to be both necessary and sufficient for a diagnosis. While they were regularly accompanied by RRBIs, and other narrow constructs such as emotion regulation difficulties, these were neither sufficient nor necessary.

Narrow constructs
Surprisingly, in all narrow constructs explored that contributed directly to the conceptualisation of autism, girls and boys with autism were thought to be equally impaired. Where they differed were constructs related, but ultimately secondary, to the conceptualisation of autism: girls were thought to have greater social awareness, social motivation, and emotional recognition. Further, girls tended to cope by internalising, while boys tended toward externalising.

Behavioural exemplars
Behaviourally, girls and boys with autism were seen as presenting very differently. Participants thought girls tended to mask and hide their difficulties through copying others, and avoided any outward displays of anger or
disruptive behaviour, unlike boys. Therefore, girls’ autism-related behaviours can be subtler than males, despite the underlying impairment being equal.

**Reasons for gender difference in behavioural exemplars**

Gender differences in the behavioural exemplars of autism should not be attributed as solely a result of the few differences in narrow constructs. Broader effects of culture and biology that produce the same (diffuse) gender differences seen in the general population will also influence people with autism, but potentially in unique ways. For example, gender-based toy selection.

Vervet monkeys exhibit the same gender bias in toy selection as humans (Alexander and Hines, 2002), implying biological causation. Yet, Langlois and Downs (1980) found that human children received differential rewards from parents and peers for playing with same-sex vs cross-sex toys, implicating cultural effects. Finally, Knickmayer, Wheelwright and Baron-Cohen (2008) found that while children with autism showed culturally accepted sex differences for imaginative play, girls with autism did not show female-typical play preferences for more concrete play, such as skipping rope, playing with hair or dancing, suggesting that autism may have an overarching effect. Therefore, autism may moderate the effects of both biology and culture’s influence on gendered behaviour.

Biology and culture may also contribute to the creation of gender differences seen in narrow constructs. For example, parents’ play with daughters tends to be more verbal and conversational than with their sons (Clearfield and Nelson, 2006). In this way, parents’ behaviour (culture) could impact on a child’s social ability (a narrow construct). Further research may identify how biology and culture interact with autism to create the gender differences in narrow constructs and behavioural exemplars seen here.
Culture had a direct impact on how girls with autism were perceived, and therefore treated. As autism is seen as a predominantly male condition, girls are less likely to be recognised, their diagnoses harder to accept, and their support poorer than boys. Therefore, further research on how girls with autism present, and greater awareness of this presentation, is required to ensure girls are not unfairly prejudiced against receiving a diagnosis and getting support.

*A female presentation?*
Arguably, it is wrong to characterise one presentation as feminine and the other masculine. Gender differences in biology and culture may make a different set of narrow constructs and behaviours more likely, depending on gender. Yet, boys may show a more female-typical set of narrow constructs and behaviours, and vice-versa for girls. It may therefore be more accurate to consider autism presentations in terms of trans-diagnostic constructs such as social awareness, emotional recognition, and internalising/externalising, rather than by gender. Thus, the issue of accurate identification and diagnosis of girls with autism can be reframed to accurate identification and diagnosis of autism in those higher levels of social awareness, social drive, internalising coping strategies, and emotional recognition. This presentation is less recognised and harder to diagnose, and require a level of experience and confidence on the part of the clinician.

*Diagnostic implications*
Three implications for diagnostic criteria emerge from the broad conception of autism. First, it appears the definition of autism in the current diagnostic criteria is not inherently gender biased, and is equally applicable across genders. Second, the diagnostic criteria only capture part of autism, with some areas such as motor clumsiness, executive functioning and emotional dysregulation missed, despite being important indicators for clinicians. Finally, clinicians’ conceptions of social interaction and communication difficulties as both necessary and sufficient, questions the conception of
autism used in the criteria. Autism may not require RRBIs, allowing their removal from the criteria. Instead, RRBIs and other narrow constructs might be better conceptualised as markers, correlates or secondary effects that should be investigated when assessing.

Reflections

It is notable that the expectations of the primary researcher changed over the course of the project. Initially, it was expected by the primary researcher that there would be a difference in how autism affects boys and girls, and that a specific ‘male’ and ‘female’ presentation (and potentially diagnostic criteria) may be found. On the contrary, arguments were consistently made during the interviews indicating that girls and boys with autism are affected by autism in the same way. While it is possible this initial bias may have impacted the results, any impact of this bias is likely to be minimal. This is evidenced by the fact that coding took place after all interviews had been completed and the researcher’s perspective had already changed in line with the interviews, and that the resulting analysis runs contrary to the primary researcher’s initial expectations.

During the initial pilot interview, the primary researcher noted that, on occasion, questions such as “how do boys and girls with autism differ in x?” were used, instead of “do boys and girls with autism differ in x?”. Further, in trying to piece together a working model of each participant’s understanding of autism, questions such as “given your earlier statements x and y, does this mean z?” were occasionally used. Both types of questions had the potential to influence participants’ responses. While the former was something the primary researcher tried to minimise, the latter was felt necessary in gaining a full picture of the participants working model of autism.

From part way through the first interview, the primary researcher attempted to address both potentially biasing statements. Participants were told that the primary researcher’s questioning of gender difference in an area did not
mean that a gender difference was expected or required, and that a null response was equally as valuable as an indication of gender difference. Similarly, the use of questions to probe how participants’ working model of autism was explained, and that contradictions in their models were acceptable. Further, when null or contradictory responses were given, the primary researcher would (particularly if the participant appeared uneasy giving such an answer) reinforce the acceptability and value of such responses. The presence of these questions, and the countermeasures taken were discussed in supervision by all three authors.

Strengths and Limitations
This study facilitated the exploration of autism outwith the confines of diagnostic criteria. While qualitative approaches are limited in their generalisability, many of the themes generated are supported by previous research. For example, girls with autism show greater social drive and ability (Head, McGillivray and Stokes, 2014), less externalising behaviour, and greater social skills than boys (Hiller, Young and Webber, 2014). Further, a qualitative study by Bargiela, Steward and Mandy (2016) found themes of “you’re not autistic” and “pretending to be normal”, complementing our findings that autism is not accepted for girls, and that girls are more likely to mask. Collectively, this suggests that these findings are somewhat generalisable. Indeed, the unique contribution of this study is not in identifying new areas, but in constructing a narrative of how these areas interlink and interact over time for people with autism. In this sense, while these links may be ultimately unfalsifiable, they do provide an ecologically valid, functioning framework that clinicians and researchers can apply when considering the development and presentation of autism in boys and girls.

During interviews, participants were asked to only consider children without a learning disability. Combined with theme 3.5 (suggesting gender differences are predominantly at the high-functioning end of the autism spectrum) these
results may only inform presentations of boys and girls without a learning disability. However, results relating to the core conception of autism may have more applicability, as this will likely be formed from all their experiences of autism, including from those with a comorbid learning disability.

As participants were asked to only consider children up to age 18 when talking about their experience, these results may not be applicable across the lifespan. Yet, while the issues faced by adults with autism, and their presentation may be different to children, the broad and narrow constructs underlying autism are less likely to change, and so may have some applicability. For example, Bargiela, Steward and Mandy (2016) identified similar challenges faced by women that this study identified for girls.

Replication of this study with other stakeholders in autism is needed. Clinical Psychologists can only offer one perspective, and may, by virtue of their training, be inclined to overweight internal thought process and thinking styles, as well as observable behaviours such as RRBIs. In comparison, speech and language therapists may put greater emphasis on the details of language use and nonverbal communication. Equally, psychiatrists and paediatricians might, through their work, be more inclined to stick closer to existing diagnostic criteria, and put greater weight on issues of differential diagnosis, comorbidities and aetiologies. Therefore, replication with people with autism, their carers, educators, or other healthcare professionals may confirm our findings, identify areas missed, or offer a contrasting perspective. Comparing the perspectives of multiple stakeholders in autism would increase the validity of these results.

Given the gender bias in the population, participants likely had fewer girls contributing to their conception of autism. However, given the number of participants, it was felt any outliers in any one clinician’s experience would be balanced out. A more likely confounder is confirmation bias. In asking about differences, participants may have been more likely to consider and
overweight cases where girls presentation differed from boys, stood out, or fitted with existing research. While this bias is impossible to avoid and should be considered, given the strength of existing empirical evidence, it is more parsimonious to cautiously assume it had limited influence.

**Conclusions**

For clinicians, the core of autism was a deficit in social interaction and communication, with an expanded, more inclusive triadic view capturing many of the common comorbid or secondary factors associated with autism. Girls and boys with autism were considered equally affected by autism, but coped with it in different ways. Girls tended to be more socially aware, socially motivated, and better at emotional recognition, compared to boys, leading to masking. Girls also tended to try to cope alone, internalising their difficulties, while boys externalised their difficulties. While gender differences in biology and culture may have influenced this presentation, it is only an influence, and some boys can present similarly to girls. Therefore, using trans-diagnostic factors, such as social awareness, has greater validity in considering the debate on gender differences in autism. Further research on the relationship between culture, biology, and these gender differences, and on other professionals’ perspectives, will help form a more ecologically valid model of autism.
References


Full text BPS formatted references


Appendices
Appendix 1A: *Autism: International Journal of Research and Practice* style guidelines

In respect to copyright, the full style guidance is not reproduced in full here, but can be accessed at [https://uk.sagepub.com/en-gb/eur/journal/autism#submission-guidelines](https://uk.sagepub.com/en-gb/eur/journal/autism#submission-guidelines).

Pertinent style guidance is quoted here:

3. Article types

The Journal considers the following kinds of article for publication:

1. **Research Reports.** *Full papers* describing new empirical findings;

2. **Review Articles.**
   - (a) *general reviews that provide a synthesis of an area of autism research;*
   - (b) *critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.*

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

7.1 Research ethics

All papers reporting animal and human studies must include whether written consent was obtained from the local Ethics Committee or Institutional Review Board. **Please ensure that you have provided the full name and institution of the review committee and an Ethics Committee reference number.**

We accept manuscripts that report human and/or animal studies for publication only if it is made clear that investigations were carried out to a
high ethical standard. Studies in humans which might be interpreted as experimental (e.g. controlled trials) should conform to the Declaration of Helsinki [http://www.wma.net/en/30publications/10policies/b3/index.html] and typescripts must include a statement that the research protocol was approved by the appropriate ethical committee.

7.3 Statistical analyses
Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are usually required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

7.5 Prisma

*Autism* requires a completed PRISMA checklist and flow diagram as a condition of submission when reporting the results of a systematic review. Templates for these can be found on the PRISMA website [www.prisma-statement.org](http://www.prisma-statement.org). You should ensure that, at minimum, your article reports content addressed by each item of the checklist. Meeting these basic reporting requirements will greatly improve the value of your systematic review and may enhance its chances for eventual publication.

9.2 Journal Style

*Autism* conforms to the SAGE house style [https://studysites.uk.sagepub.com/repository/binaries/pdf/SAGE_UK_style_guide_short.pdf].

9.3 Reference Style

9.4. Manuscript Preparation
The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. SI units should be used throughout the text.

9.4.2 Corresponding Author Contact details
Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.
Appendix 1B: Quality Criteria for Systematic Review

Template created by Paul Morris and colleagues, University of Edinburgh

Write Systematic Review Question(s) Here:

Is there a gender differences in scores on the Block Design Task in people with Autism

<table>
<thead>
<tr>
<th>Quality Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Sample Balance</td>
</tr>
<tr>
<td>2 Exclusion of other conditions</td>
</tr>
<tr>
<td>3 Diagnosis validated</td>
</tr>
<tr>
<td>4 Homogeneous groups</td>
</tr>
<tr>
<td>5 Males and females comparable</td>
</tr>
<tr>
<td>6 Achieved statistical power</td>
</tr>
<tr>
<td>7 Appropriate statistical analysis</td>
</tr>
<tr>
<td>8 Appropriate reporting of statistical analysis</td>
</tr>
</tbody>
</table>

Operationalisation of Quality Criteria

Ensure these are outlined in a manner that makes it clear which category studies should be allocated to:

1 – Sample Balance

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Male and female groups are within 3:4 ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Male and female groups are within 1:4 ratio</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Male and female groups have greater than 1:4 ratio</td>
</tr>
<tr>
<td>Not addressed</td>
<td>----</td>
</tr>
<tr>
<td>Not reported</td>
<td>Size of male and female groups are not individually reported</td>
</tr>
<tr>
<td>Not applicable</td>
<td>----</td>
</tr>
</tbody>
</table>

2 – Exclusion of other conditions

<table>
<thead>
<tr>
<th>Well covered</th>
<th>The study reports on and excludes a number of other conditions likely to affect block design sores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>The study excludes participants with an IQ below 70 or a learning disability, but no other conditions</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Reports other diagnosis which may affect performance on block design, but not excluded</td>
</tr>
<tr>
<td>------------------</td>
<td>---------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Not addressed</td>
<td>No effort to control for other conditions or average IQ below 70</td>
</tr>
<tr>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Not applicable</td>
<td>----</td>
</tr>
<tr>
<td>Notes</td>
<td></td>
</tr>
</tbody>
</table>

### 3 – Diagnosis validated

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Study validates diagnosis of ASD with at least two professionals AND a structured measure (ADOS, ADI, etc)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Study validates diagnosis of ASD with one or more professionals AND/OR a structured measure (ADOS, ADI, etc)</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Study uses records to validate diagnosis</td>
</tr>
<tr>
<td>Not addressed</td>
<td>Study goes on self/parent report of diagnosis</td>
</tr>
<tr>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Not applicable</td>
<td>----</td>
</tr>
<tr>
<td>Notes</td>
<td></td>
</tr>
</tbody>
</table>

### 4 – Homogeneous groups

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Groups can be reasonably assumed to be homogenous within themselves. Male and female groups can be reasonably assumed to be homogeneous. E.g similar recruitment source, similar IQs, ages, etc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Male and female groups are likely to be homogeneous, but limited reporting/some minor differences unlikely to be significant</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Male and female groups are not homogeneous, with some differences which might have a small effect on results</td>
</tr>
<tr>
<td>Not addressed</td>
<td>Male and female groups are not homogeneous, with differences enough to question the validity of the results</td>
</tr>
<tr>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Not applicable</td>
<td>----</td>
</tr>
<tr>
<td>Notes</td>
<td></td>
</tr>
</tbody>
</table>

### 5 – Males and females comparable

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Males and female groups are directly comparable e.g similar recruitment source, IQs, Ages, etc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Male and female groups are similar, but limited reporting or some minor differences unlikely to impact results</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Male and female groups are vaguely similar, but some differences which may impact the results OR key information about males and females amalgamated.</td>
</tr>
<tr>
<td>------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Not addressed</td>
<td>Male and female groups are so dissimilar as to likely invalidate the results.</td>
</tr>
<tr>
<td>Not reported</td>
<td>---</td>
</tr>
<tr>
<td>Not applicable</td>
<td>---</td>
</tr>
<tr>
<td>Notes</td>
<td></td>
</tr>
</tbody>
</table>

**6 – Achieved statistical power**

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Statistical power of 0.8 or above</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Statistical power of 0.6 or above</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Statistical power of 0.5 or above</td>
</tr>
<tr>
<td>Not addressed</td>
<td>Statistical power cannot be calculated</td>
</tr>
<tr>
<td>Not reported</td>
<td>---</td>
</tr>
<tr>
<td>Not applicable</td>
<td>---</td>
</tr>
<tr>
<td>Notes</td>
<td>Calculation based on Colom et al (2002)</td>
</tr>
</tbody>
</table>

**7 – Appropriate statistical analysis**

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Uses a statistical comparison appropriate to the data, including checking the suitability of the data (skewness, kurtosis, etc)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Uses a statistical comparison appropriate to the data, but no details on pre/post analysis to ensure the comparison can handle the data</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Uses an inappropriate statistical comparison, or uses a comparison which cannot handle the data</td>
</tr>
<tr>
<td>Not addressed</td>
<td>Does not compare males and females on block design</td>
</tr>
<tr>
<td>Not reported</td>
<td>Does not report what statistical analysis it did</td>
</tr>
<tr>
<td>Not applicable</td>
<td>---</td>
</tr>
<tr>
<td>Notes</td>
<td></td>
</tr>
</tbody>
</table>

**8 – Appropriate reporting of statistical analysis**

<table>
<thead>
<tr>
<th>Well covered</th>
<th>Reports all relevant statistical information (degrees of freedom, effect size, f and p values, etc)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequately addressed</td>
<td>Reports a p value</td>
</tr>
<tr>
<td>Poorly addressed</td>
<td>Reports overall significance/non-significance</td>
</tr>
<tr>
<td>Not addressed</td>
<td>---</td>
</tr>
<tr>
<td>Not reported</td>
<td>Does not report significance</td>
</tr>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 1C: Comparison of studies included/excluded from Muth, Honekopp and Falter (2014)

<table>
<thead>
<tr>
<th>Name</th>
<th>Included in Muth paper</th>
<th>Included in analysis</th>
<th>Reason for exclusion</th>
<th>Effect size (d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pellicano (2006)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
<td>1.75</td>
</tr>
<tr>
<td>Ishida (2009)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>1.20</td>
</tr>
<tr>
<td>Soulieres (2011)</td>
<td>Yes</td>
<td>No</td>
<td>Split experimental group based on ability on the BDT</td>
<td>1.15</td>
</tr>
<tr>
<td>Caron (2006)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
<td>1.12</td>
</tr>
<tr>
<td>Pring (2010)</td>
<td>Yes</td>
<td>No</td>
<td>Not reporting gender makeup of groups</td>
<td>1.09</td>
</tr>
<tr>
<td>Morgan (2003)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.76</td>
</tr>
<tr>
<td>Shah and Frith (1993)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
<td>0.63</td>
</tr>
<tr>
<td>Rumsey and Hamburger (1988)</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td>0.61</td>
</tr>
<tr>
<td>Shah and Frith (1993)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
<td>0.51</td>
</tr>
<tr>
<td>Smalley and Asarnow (1990)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.48</td>
</tr>
<tr>
<td>Planche and Lemoniner (2011)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.46</td>
</tr>
<tr>
<td>Van Lang (2006)</td>
<td>Yes</td>
<td>No</td>
<td>Inclusion of children with a learning disability.</td>
<td>0.41</td>
</tr>
<tr>
<td>Bolte (2011)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.26</td>
</tr>
<tr>
<td>Bolte (2007)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.25</td>
</tr>
<tr>
<td>Ropar (2001)</td>
<td>Yes</td>
<td>No</td>
<td>No clear comparable control group. Verbal mental age notably below chronological age in experimental group</td>
<td>0.16</td>
</tr>
<tr>
<td>Ozonoff (1991)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.15</td>
</tr>
<tr>
<td>Reference</td>
<td>Results</td>
<td>Gender</td>
<td>Other Notes</td>
<td>Effect Size</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------</td>
<td>--------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Williams, Goldstein and Minshew (2006)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>0.15</td>
</tr>
<tr>
<td>Edgin and Pennington (2005)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>-0.06</td>
</tr>
<tr>
<td>Spek et al (2011)</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>-0.18</td>
</tr>
<tr>
<td>Drake (2013)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
<td>-0.31</td>
</tr>
<tr>
<td>Holdnack et al (2011)</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td>-0.31</td>
</tr>
<tr>
<td>Pring et al (1995)</td>
<td>Yes</td>
<td>No</td>
<td>Not reporting gender makeup of groups</td>
<td>-0.39</td>
</tr>
<tr>
<td>Bolte (2008)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
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<tr>
<td>Kaland (2007)</td>
<td>Yes</td>
<td>No</td>
<td>Not Wechsler BDT</td>
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<tr>
<td>Burnette (2005)</td>
<td>Yes</td>
<td>No</td>
<td>Including children with an intellectual disability.</td>
<td>-0.45</td>
</tr>
<tr>
<td>Scheurich (2010)</td>
<td>Yes</td>
<td>No</td>
<td>Text not in English.</td>
<td>-0.46</td>
</tr>
</tbody>
</table>
Appendix 1D: Meta-Analysis and Meta-Regression Calculation

Appendix 1D is presented on the following 3 pages
### Appendix 1E: Prisma Checklist

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>1</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>14</td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>15</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>17-21</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>21</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>22</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>22</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>22</td>
</tr>
<tr>
<td>Search</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td>22</td>
<td></td>
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<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td>22-25, 32, 34</td>
<td></td>
</tr>
<tr>
<td>Data collection process</td>
<td>Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Data items</td>
<td>List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
<td>26-27, 32, 34</td>
<td></td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
<td>24-25, 28, 35</td>
<td></td>
</tr>
<tr>
<td>Summary measures</td>
<td>State the principal summary measures (e.g., risk ratio, difference in means).</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis.</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>15</td>
<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
<td>17-19, 35</td>
</tr>
<tr>
<td>----------------------------</td>
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</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
<td>36</td>
</tr>
</tbody>
</table>

**RESULTS**

<table>
<thead>
<tr>
<th>Study selection</th>
<th>17</th>
<th>Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.</th>
<th>22-24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study characteristics</td>
<td>18</td>
<td>For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.</td>
<td>26-27, 40-41</td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>19</td>
<td>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</td>
<td>28</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
<td>37, 41-41</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
<td>35</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see Item 15).</td>
<td>35</td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).</td>
<td>36</td>
</tr>
</tbody>
</table>

**DISCUSSION**

<table>
<thead>
<tr>
<th>Summary of evidence</th>
<th>24</th>
<th>Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).</th>
<th>31, 42-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limitations</td>
<td>25</td>
<td>Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).</td>
<td>45-48</td>
</tr>
<tr>
<td>Conclusions</td>
<td>26</td>
<td>Provide a general interpretation of the results in the context of other evidence, and implications for future research.</td>
<td>31, 47-49</td>
</tr>
<tr>
<td>FUNDING</td>
<td>27</td>
<td>Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2A: Invitation to take part

Letter sent as an e-mail via heads of child mental health services:

To Heads of Child Services,

My name is Joshua Muggleton, I'm a Trainee Clinical Psychologist with NHS Fife and the University of Edinburgh. I'm contacting you to enquire as to whether you or any staff within your Department would be interested in an upcoming project for my doctoral thesis.

The project is a qualitative study, interviewing Clinical Psychologists about their thoughts, experiences and strategies diagnosing children with ASD (0-18 without a comorbid LD), and in particular, in diagnosing girls with ASD. We wish to interview clinicians who are involved in the diagnosis of ASD in children. We anticipate the study will run from January 2016 for one year, and will involve one 60-90 minute interview. Our intention is to look at whether there are particular differences in the way that decisions about diagnosis are made for girls, as well as highlighting difficulties that clinicians might experience in the assessment and diagnosis of ASD in girls. Our hope is that as a result of this research, we will inform the debate as to if and how girls present with ASD differently, and the current diagnostic criteria’s ability to capture any difference. We hope that this will contribute to any future guidance on the diagnosis of ASD in girls.

At present, we are not yet recruiting, but we would like to identify any Departments that might be interested in receiving information about the study, and being involved. In particular, we would like to identify services where there are Clinical Psychologists involved in the diagnosis of ASD, and where you would be willing for me to contact you again about the study toward the end of 2015 (when we begin recruiting).
If this is a project you, or any clinicians within your service, might be interested in, I would be very grateful if you could let me know. If so, I will be in contact again later in the year with further details when we begin recruiting for the study. Should you have any questions, or wish to discuss the project further at this stage, please do not hesitate to get in touch with myself, or my supervisors, Katrina Johnston (NHS Fife) or Ken MacMahon (University of Edinburgh).

Many thanks

Josh
Appendix 2B: Participant information letter and consent form

Appendix 2B is presented on the following 5 pages
Information Sheet

Project title: A qualitative study of highly experienced clinical psychologists’ understanding of Autism Spectrum Disorders in girls

INVITATION
You are being invited to take part in a research project investigating how highly experienced clinical psychologists think about Autism Spectrum Disorders (ASD). In particular, we are interested in how you diagnose and conceptualise the presentation of ASD in girls without a learning disability. We hope to add to the literature on the presentation of ASD in children, and whether the current diagnostic criteria adequately capture the disorder across the genders. You have been invited based on your experience assessing children and young people, both male and female, for ASDs.

This research is being undertaken as part of the doctoral thesis of Joshua Muggleton, currently studying for a doctorate in Clinical Psychology at the University of Edinburgh, and training at NHS Fife. This project is conducted under the supervision of Dr Ken MacMahon, Senior Lecturer in Clinical Psychology at the University of Edinburgh, and Dr Katrina Johnston, Clinical Psychologist at NHS Fife. This project has been approved by the University of Edinburgh Ethics Committee (ID NUMBER HERE), and is registered with NHS Fife Research and Development service.

WHAT WILL HAPPEN
It is up to you whether you wish to take part. If you wish to take part, you will be asked to liaise with Joshua in order to arrange for a convenient time to meet to be interviewed. This is ideally in person, but it may be possible to meet over Skype if that is required. If you are able to meet in person, you will be asked to arrange for a quiet room for the interview to take place in. The interview will last approximately 60-90 minutes and will be audio recorded. The questions you will be asked relate to:

- What you think autism is,
- Whether you think boys and girls with autism present differently,
- Whether diagnosing girls or boys is more difficult,
- Whether there are any differences in how girls manage their autism,
- Whether girls have more difficulty meeting diagnostic criteria,

During the interview, Joshua will prompt you with questions and reflections to explore your understanding. He will also ask for case examples to illustrate your points. You will be asked to avoid providing identifying information, such as full names. If you do, inadvertently, do this, those details will not be transcribed from the recording.
Once the interview is complete, it will be analysed using Thematic Analysis. Once complete, you will be offered the chance to review the analysis for comment before it is finalised. It is up to you whether or not you wish to read and comment on the analysis.

Once complete, the research will be written up as part of Joshua’s doctoral thesis, and submitted to journals for publication. You may have an electronic copy of the write up if you wish.

TIME COMMITMENT
The interview is expected to last 60-90 minutes. We anticipate that reading and commenting on the analysis would not take more than 30 minutes; however, this is optional and not a requirement for participation.

PARTICIPANTS’ RIGHTS
You may decide to stop the interview at any time, without providing a reason.

We may wish to use short anonymised quotes from your transcript for illustrative purposes in publications. These will be carefully selected to ensure that you cannot be identified. However, if you would rather no quotes were used from your transcript, please inform Joshua of this and a signed record of this will be kept.

You have the right to ask that your recording and transcript are destroyed at any time. However, the analytic method used in this study means that it is impossible to withdraw data when it has been included in the analysis. Therefore, analysis on your data will not start until at least 7 days after the interview. This means **you have up to 7 days after the interview to withdraw all your data.** After this point, the analysis on your transcript may have started. Any request made after 7 days will be honoured as much as is practically possible. Any data analysis will stop, and any remaining data will not be analysed. Similarly, all transcripts and audio recordings will be destroyed, preventing your data being used for illustrative purposes in any publications, or for other studies. However, we will not be able to withdraw any data from the analysis if it has already been included.

Please feel free to ask questions at any point. If you have any questions as a result of reading this information sheet, you should ask the Joshua before the study begins.

BENEFITS AND RISKS
This study is not anticipated to result in any risks to yourself. It is anticipated that during the course of the interview, confidential identifiable information may be revealed, particularly when asking for case examples. You are kindly asked to avoid using identifying details when giving case examples during the interview. However, should this happen, any information that is clearly identifiable will be removed from the analysis during transcription.

Should you reveal any information that causes the researcher concern over your fitness to practice or patient safety, the researcher will discuss this with both his
clinical and academic supervisors. If, after this, it is felt that there might be a risk to patients, the researcher’s supervisors will make contact with you for further clarification. If there are remaining concerns, your line manager (or the HCPC if practicing independently) will be contacted in case of concerns over fitness to practice. If these concerns are with regards to children or vulnerable adults, and the supervisors do not feel that the risks are being adequately managed, they will make contact with the relevant Social Work department to raise their concerns. These procedures have been put in place for this study to ensure the safety of children and vulnerable adults.

In trials, participants have reported that the interview was a thought provoking and enjoyable process, and we hope you will find it similarly positive. We hope that we will add to the literature on the presentation of autism in girls and boys, and the debate on whether the current diagnostic criteria are representative.

COST, REIMBURSEMENT AND COMPENSATION
Your participation in this study is voluntary. We are unfortunately unable to provide any reimbursement for time provided.

CONFIDENTIALITY/ANONYMITY
Joshua will transcribe the recording, during which any identifying details will be removed. Transcripts will use pseudonyms to identify each participant. There will be no record linking each participant to their pseudonym. Transcripts will be viewed by Drs MacMahon and Johnston. In addition, your non-identifiable transcript will be stored at the University of Edinburgh in a secure data network. The data will only be shared with other researchers for valid research requests.

The analysis, write up, and results of this study will be submitted as part of Joshua’s thesis, and to academic journals. The analysis may include quotes (using pseudonyms), and may be presented at conferences. However, as noted before, you have the right to refuse direct quotations, from yourself, being used in write-up.

ORGANISATION OF THE RESEARCH
This study has been organised/sponsored by the University of Edinburgh

FOR FURTHER INFORMATION
Joshua will be glad to answer your questions about this study at any time, and can inform you about the results of the study once data collection is complete. You may contact him at joshuamuggleton@nhs.net. Alternatively, his supervisors can be contacted at Ken.MacMahon@ed.ac.uk, and KatrinaJohnston@nhs.net.

If you wish to make a complaint about a person in the study to someone independent of the team, please contact Angus MacBeth at angus.macbeth@ed.ac.uk. To complain about the study as a whole, please contact the University of Edinburgh’s Research Governance Team via e-mail at researchgovernance@ed.ac.uk.
A qualitative study of highly experienced clinical psychologists’ understanding of Autism Spectrum Disorders in girls

Please read the following points, initialling the box to confirm your understanding and agreement.

☐ You have read and understood the Participant Information Sheet (version 1, 08/09/2015)

☐ Questions about your participation in this study have been answered satisfactorily

☐ You are willing for to take part in this research study voluntarily

☐ You are aware that you have a right to withdraw your data from this study at any time.

☐ You understand that your interview will be audio recorded (and, for skype interviews, video recorded).

☐ You understand that after 7 days from the date of the interview it may no longer be possible to withdraw some or all of your data.

☐ You are aware that verbatim quotes from this interview may be used in publications, although quotes will not be identifiable to individuals

☐ You are aware that you are entitled to request that, at any time, quotes from this interview are not used in any materials published after the time the request is made.

☐ You agree that a non-identifiable transcript of this interview can be securely stored at the University of Edinburgh, where it will be only accessible by researchers making a valid request to use the data for research.

☐ You understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor (University of Edinburgh) or from the/other NHS Board(s) where it is...
relevant to my taking part in this research. You give permission for those individuals to have access to my data

By signing below, you are agreeing that you have read, understand and agree to the points above, and are willing to take part:

Participant name:

Title:

Signature:

Date:

Person obtaining consent name:

Signature:

Date:

Original (x1) copy retained in site file. Copy (x1) to be retained by the participant.
Appendix 2C: Interview Schedule

Broad Construct

Based on your clinical experience, what do you think autism is?

Does your clinical experience of autism and its diagnosis differ from what you might see in a diagnostic manual like ICD-10 or DSM-V?

Gender specific narrow constructs

Do you think autism presents differently in girls and boys? If so, how? If not, what do they have in common?

Follow-up prompts (if needed)

- Are there differences in: (the following areas may be used as follow up prompts, if needed, to ensure all areas are covered)
  - Social interaction
    - Social awareness
    - Social drive
    - Demand avoidance
    - Passivity/loner
    - How others interact with/support/socialize with that person?
  - Communication
    - Linguistic ability
  - Restricted and repetitive interests and behaviours
    - Intensity
    - Quality
    - Area
  - Rigidity
    - Of thought
    - Perfectionism
    - Controlling
    - Imagination/social imagination
    - Separating fantasy from reality
  - Emotional recognition/sensitivity in self and others

Can you tell me about a case, or more than one, where you've found these differences?

Diagnosis

Do you have a memorable case where you had to assess a girl for ASD? Can you talk me through it?

Follow-up prompts (if needed)

- How did you handle it?
• What tipped the balance to allow you to decide?

Do you think that there’s an under or over diagnosis of autism in girls?

Do you think there’s times when girls are given the wrong diagnosis? What are the misdiagnoses? Does the same thing happen with boys?

Are comorbid conditions more frequent in girls?

Have you, in your clinical experience, found that there are there areas where girls appear have difficulty meeting the requirements for a diagnosis?

What, if anything, do you do differently when assessing girls?

Post-diagnostic Support

Do girls manage their difficulties with ASD differently from boys? If so, can you tell me how? Can you give me a case example?
Appendix 2D: Sample of descriptors

The following is a sample of the first 100 descriptors by alphabetical order.

Note: “ALL” is short hand for all boys and girls with and without autism. “ASD” is short hand for autism/people with autism. “dx” is short hand for diagnosis. “dxed” is short hand for diagnosed. “dxing” is short had for diagnosing. ADOS stands for Autism Diagnostic Observation Schedule. ABAS stands for Adaptive Behaviour Assessment System. CAMHS stands for Child and Adolescent Mental Health Services.

- (social) imagination linked to intellectual ability in ASD boys and ASD girls
- 3rd part of triad is repetitive behaviour, rigid thinking, and sensory stuff
- 8-9 year old ASD girl might find peer friendships too verbal, so observe girls to copy them - not social awareness but response to social demands
- A lot of ASD girls know what support they need and will be frustrated if not given it or not followed
- A lot of children with ASD presenting to CAMHS with Anxiety
- A lot of evidence supporting a dx can be quite poor or contradictory, even when the person gets a dx
- A lot of kids with MH problems meet parts of criteria, but often not for long
- A person can get a dx even when the evidence is poor or contradictory
- A person should score in each area of the triad
- A person with other autistic traits but no social communication problems would not be thought of as having autism
- A sense of a person not being typical in their presentation for someone of their age indicator for dx
- A strengths and weaknesses view - what is this person good at in the triad, what do they struggle with
• ABAS IQ discrepancy common to ASD boys and ASD girls, but useful for undxed cases, often girls
• Ability to use technology, such as AI to develop social communication skills in people with Autism
• Able to rely more in school report for boy than girl during Dx Ax
• Administers ADOS differently to ASD girls than to ASD boys
• Adolescent girls friendships more about gossip, relationships, being cool, etc
• Adolescent girls social interactions become more complex
• Adolescent girls social relationships more complex
• ADOS able to discriminate between ASD and trauma
• ADOS algorithm may not be brilliant at picking up girls, but it is ok
• ADOS and ADI may not be sensitive to ASD girls
• ADOS and ADI not scored more leniently for girls or boys
• ADOs and ADI third biggest error of measurement
• ADOS does not pick up on eccentricities, unusual ideas, etc
• ADOS doesn't tell you about how a person interacts in relationships, or would be in relationships
• ADOS great instrument, but not good at picking up subtle presentations or difficulties with insight and social interactions
• ADOS might not pick up on girls learned nature of ASD girls EC, facial expressions, etc
• ADOS might not pick up on subtle differences between genuine social imagination and intellectualised social imagination
• ADOS might not pick up on subtle female presentations
• ADOS not great for ASD girls, but best we have
• ADOS scores are a tool, a measure, not a dx
• ADOS scoring is subject to interpretation - need to be able to interpret girls correctly
• ADOS, Hx, and discussion helps shift from Behavioural problems to 'this could be ASD'
• Adults, parents, teachers, interact with children differently depending on their gender
• AF and HF kids can mask RRBIs
• AF and HF people with ASD not picking up on social cues
• Against abandoning the ADOS because girls might score differently
• Age can effect perceptions of what is socially or culturally appropriate
• Aggression in one context but not others does not fit with abuse, neglect, poor parenting, etc
• ALL boys externalise emotions
• ALL boys externalising results in difficult behaviour
• ALL boys friendships more about playing games
• ALL boys likely to develop later, and need more help with social emotional communication
• ALL boys social engagement is more practical, and requires less social skill
• ALL females are more social or have a higher social drive than ALL males
• ALL females want to connect more than ALL males
• ALL girls develop faster and need less help with social emotional communication
• ALL girls friendships about chat
• ALL girls internalise emotions
• ALL girls internalising results in anxiety and low mood
• ALL girls likely more vulnerable to societal expectations than ALL boys
• ALL girls more compliant, ALL boys more refusing
• ALL girls tend to develop quicker, use language quicker, so will have a different social experience to boys
• ALL girls tend to develop slower, so more rough and tumble play, leading to a different social experience
• All post dx support offered equally to boys and girls
• All things being equal, ASD girls appear to develop better social competence than ASD boys
• Anime and more creative interests like fan fiction common as special interests in ASD girls
• Anxiety in ASD due to difficulties in other areas -of the triad-
• Anxiety in ASD girls comes out as crying, upset, withdrawal, etc
• Anxiety in girls with ASD often enough to be a MH issue
• Anxiety often correct dx, but underpinned by ASD
• ANY good answer needs to be probed to see if learned, or if genuine understanding
• Any person with ASD, if trying to make friends and interact socially, has social drive
• Anything to do with social interaction and communication is one part of the dyad
• Apply same dx criteria to girls and boys, and use same assessments, but thinking around them might be different
• Approval, getting into trouble, fitting in less important to ASD boys
• argues numbers of boys and girls should be same at LF and HF ends
• As adults, NT women still better than NT men at social awareness, generalisation, etc
• As ASD boys kick off more, their difficulties are flagged because it is a problem for other people
• As ASD girls who tend to come later tend to be higher functioning, so have insight and social awareness
• As depression, attachment, MH and LD can look like ASD, adds complexity, and uncertainty over which hypothesis
• As girls with ASD don't present typically, teachers more likely to help quirky warm ASD boys
• As girls with ASD less likely to have early language delay, less likely to be picked up early
• As NT girls talk more about emotions, ASD girls have greater opportunities to learn about emotions
• As social cognition, particularly in NT boys improves in coming years, ASD dx will become easier as they will stand out more
• ASD - lots of different aetiologies, slightly different presentations, but boys and girls have the same outcomes (burden, difficulties, etc)
• ASD and Attachment separate conceptually, but can be very similar in presentation - subtle distinction
• ASD and girls don't go together for people unless comorbid LD
• ASD and LD - RRBIs and attempt to exert control with regards to executive dysfunctions
• ASD and NT girls are more inclined to be social and copy
• ASD becomes more obvious as less energy-effort/etc put into maintaining mask
• ASD boy finds social demands too complex, so plays the class clown. Not lack of social awareness compared to girls, but different response strategy
• ASD boy may not like changes or violations of school rules, but ASD girl will become vocal and passionate about them
• ASD boy tier 3 queries tend to be because of attachment or cognitive issues
• ASD boys - school might say it is a bit of a problem, but problems greater or less at home
• ASD boys acting out generally, rather than explicitly going against the social hierarchy
• ASD boys and ASD girls are treated the same by others
• ASD boys and ASD girls differ in nature of social relationships
• ASD boys and ASD girls equally struggle at labelling emotions in self
• ASD boys and ASD girls get different secondary or miss diagnoses
• ASD boys and ASD girls have different emotion support needs
• ASD boys and ASD girls have high levels of rigidity
• ASD boys and ASD girls might apply rigidity of thought differently
• ASD boys and ASD girls present differently
• ASD boys and ASD girls special interests take up the same amount of time
• ASD boys and ASD girls special interests likely to take up the same amount of 'headspace'
• ASD boys and girls differ in social motivation - girls have more
• ASD boys and girls don't differ in their social awareness
• ASD boys and girls may have gender stereotyped play interest, but rigidity in play remains
Appendix 2E: Sample extracts from transcripts with descriptors

Appendix 2E is presented over the following 9 pages
Hello, I think that what's missing from the trial is the focus on sensory perception. My understanding and my work with people with autism is that what seems to be at issue is how we interpret sensory input. People with autism are often said to be sexually impaired, but the trial has been undermined by sensory issues. The trial has limits in real world applicability. The trial is undermined or explained by sensory issues. The trial suggested social skills were due to lack of social drive. Not that people are in their own world, but perceive the world differently.

The trial is undermined or explained by sensory issues. The trial is undermined or explained by sensory issues. The trial is undermined or explained by sensory issues. The trial is undermined or explained by sensory issues.

Coding Density

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So I kind of worry, like the trial is almost a symptom of the sensory issues. Yes, yes, yes, that's my understanding of it. Probably a lot of what I'm going to say is a little disjointed, and I don't know if it fits with what you know, what everybody talks about, but...
Ok. So if we try to narrow this down to boys and girls, do you think Autism presents differently in boys and girls?

Erm. Sometimes, yeah. And I've seen some girls where, you know, it's, it's classic and it is all the boxes are ticked, you know, you see repetitive behaviours and echoing and the kind of classic autistic features that people, you know, that people know about. Erm. but, er, the girls, most of the girls that I've come into contact with have probably been the older girls. You know, late primary school, teenagers. I have seen a few young girls, I work at the child development center, so I've seen a few girls there that are more of the kind of classic but even there, I've had one recently where I thought was pretty straightforward and actually didn't get a diagnosis. I wasn't able to go along to the diagnostic meeting unfortunately. I thought it was straight forward and didn't go along, but because this girl had made quite a lot of progress with her language since I had been to see her and maybe had started to learn some of the kind of social skills, I'm not sure, but she didn't get the diagnosis because people felt that, you know, she was making progress and she was. But, anyway, most of the girls that I've seen at the child development centers have been more of that kind of classic, they are flapping, and repetitive language and, erm, echoing and repetitive play and no imaginative play. You know, and quite kind of clear cut. Erm. I've, and I think there are a few where maybe the language starts to catch up a bit and maybe that starts to throw people a little bit. And then, the, as I say, the majority of the girls have been older, excellent language skills, erm, usually very lovely, very kind of endearing, and, you know, can make eye contact and smile and be very polite often. Erm. So, yeah, I think there is definitely. I've kind of gone off the track a little bit! [laugh]
Are there differences in how, er, boys and girls react to, I suppose societies expectations, demands, impositions, in terms of what strategies they use to cope? Whether it is that kind of digging their heels in, or, erm, being passive, or negotiation, or seeking help.

That's a good question. Erm. Well it get, it gets mixed up with anxiety, and er, so I think both girls and boys on the autism spectrum are very prone to erm, becoming highly anxious. And, and I think maybe girls, maybe girls more so because girls in general are more prone to anxiety. Erm. And, and so then that leads to avoiding social situations and erm, but whether you can say there is a, that, that er, have a definite identifiable difference between boys and girls, no, I don't think I'd parse it out like that. I can think of both boys and girls being very reluctant to go to family parties or, erm. No maybe not actually. Maybe girls would, I can maybe I can think of examples of girls just saying 'I can't go', and actually just being so weepy and upset then, you know, whatever was planned, they don't go to. Whereas boys, they might well go to, then get overwhelmed and have to be taken away. So not even have worked out that it is going to be too much.
Erm. We talked a bit about under and over diagnosis in girls. We also talked a bit about anxiety. And that girls quite often come with anxiety. Are there any other, other miss diagnoses?

Erm. So, emm. So some people would say that a lot of gifts will present with eating disorders as well because it is an anxiety related problem. So, certainly when I worked in an inpatient unit, we certainly did see, not sure if I would give them a full diagnosis of ASD, but certainly had some of those traits in terms of difficulty of understanding, managing their emotions, and communication difficulties. So, emm, so anxiety, eating disorders, emm. Women possibly depression. Depending on the age, emm., of the young person and how difficult their behaviour, borderline personality disorder, the kind of personality traits have certainly been, and certainly I've seen adults that have had that diagnosis for a long time, where our, where we have actually gone 'no, this is ASD', but it. Adult mental health works differently from CAMHS, and and that can be quite tricky to get people to think about a personality but certainly they have been given a personality disorder and more recently, so we have an adolescent bipolar service based here as well, and we have seen a lot of comorbidity, but also people presenting, people thinking gifts have bipolar rather than ASD. Sometimes they have both, and we are seeing a lot of that, we are seeing a lot of overlap with gifts and boys. But often people not seeing the ASD first see other diagnoses.
So, I suppose I wanted to ask a bit about, and I suppose a lot of this interview is about whether or not autism presents differently between boys and girls. Do you think it does?

I think it does absolutely. I think with boys, in my experience has been, primary school boys particularly, it is, and secondary school boys, particularly, and secondary school boys, but I’ll talk about primary kids first. I think they present more behaviourally, in terms of we are boys that have got, erm, autism spectrum. So they will be a challenge in class, they will be aggressive, not able to manage their emotions. So I think they are spotted more for whatever reason, so if they are causing a problem in class, teachers are going to pick that up and take it somewhere, perhaps a forum where they can think about what is going on. And it might not be ASD straight away, but somebody might ask that question, you know, if a mental health professional was there. So I think because they see it they do something about it. Whereas I think with girls, my feeling is and my experience and the research perhaps all fits together is that they can be much quieter with their difficulties. So in a class of what 30 kids they might be absolutely struggling socially, not ask questions, be really isolated from their peers, get it wrong, not understand emotions, have all those traits of ASD. But because they are sitting with it and it is not coming out in their behaviour, not always, but because it’s not, I think it gets missed. So it’s not until later on when perhaps we are in high school, and they have got the same set of difficulties, but as a result of not having friends, not fitting in, they are maybe self-harming or engaging in, you know, just... unhealthy coping mechanisms that then trigger an alarm bell to mental health services, and then they come into contact with us. And we might treat what we see first of all, so the self-harm, and, and then begin the fuller assessment of looking at their social communication abilities, their relationships, the longevity and the diagnosis is then later on. I think the other thing to say with that is though, very recently I’ve been involved with a wee girl who is 10, who since primary 1 has had behavioural difficulties, been really challenging in class. Very rude, not understanding social cues, social norms, and erm, there has been historical input from mental health professionals, and ASD has been on the table, off the table, on the table, off the table. And I think as well people find it very hard to get their heads around a child, a girl, presenting in a behaviourally challenging way and see it as ASD...
**Concerns over diagnostic or reclassification**

As mental disorders are highly visible, it is important to balance statistically reliable diagnostic tools and thorough measurement.

**ADHD and ADI: Specificity of measurement**

Both ADHD and ADI have high error rates of measurement, indicating the need for careful selection of tools.

**Error of measurement in ADHD**

There are several methods for assessing the error of measurement, including the use of reliability coefficients and validity indices.

**Tendency for people to not think about attachment parenting, how we learn social communication and memory strategies**

People can sometimes appear superficial and be made to fit criteria, but evidence suggests that once we start digging deeper, we can find more nuanced approaches.

**Need to question information sources in ADHD**

People can have bad days on the ADHD medications, and it is important to be cautious with how we interpret evidence.

**Coding Density**

Understanding the density of coding helps in assessing the depth and breadth of the information presented in the text.
Concerns over dx reductionism or az reductionism
Dx manuals descriptions fit mostly dx.
Need to balance statistically reliable dx and high throughput on one hand, and thinking more broadly and deeply about a case on the other
ABO and ABD (and biggest error of measurement)
Questionnaires (fail to ask about biggest error of measurement)
Informants have biggest errors of measurement
Error of measurement in As talks
Little research supporting what combination of components makes up a significant path
When a thing being looked for is path
Need for experience when dx ABD
A person can get a dx even when the evidence is poor or contradictory
A lot of evidence supporting a dx can be quite poor or contradictory, even when the person gets a dx
Tendency for people to not think about attachment, parenting, how we learn social communication and emo reg strategies
People can present with Autism on the surface and be made to fit criteria, but evidence not strong once start digging
People can have bad days on the ADOS, and it has error of measurement - need to hold a questioning position
Need to question information sources includes ADOS
Need for doubt or questioning of all bits of evidence
Coding Density
So are boys then... do you still have that... ASD in infancy almost, or that social communication we think it's going to turn into ASD... do you have that with boys as well, or is it very much more a girl thing?

I would find myself having that conversation less with parents of boys than girls. Boys seem to be a little cleaner cut. These ones where you spend ages assessing and then you bring the parents in and then you say 'I'm really sorry I'm not committing to a decision just now'. As frustrating as this is for you, and kind of explaining about developmental trajectories and, all that kind of stuff. I, find myself doing it more, would do it more for girls than boys. So the boys seem to be slightly cleaner cut and sit less in that kind of muddy grey area. Not showing enough difficulties, that they are not necessarily going to be picked up by the health visitors anyway, so you're kind of relying on schools and parents to recognize that something is out, something is... out of kilter. Erm, some of them might be in the pediatric system already if there has been, erm, a speech delay or if there has been a kind of general developmental delay or something as well, they might be in the pediatric system and, in the course of being reviewed within a child development clinic, it gets pick up. So some of them are probably picked up there anyway. The ones who aren't known, those, you know to pediatrics, and who aren't kicking off at school who is probably not the girls, they're going to be more, more difficult to kind of capture. So awareness raising without over egging it so that then everybody thinks that their child is... then try to encourage all those steps that need to happen. Now whether this, I don't know if this, I don't know him well enough to know if this potentially is a realistic goal or not. It might be completely unrealistic, or maybe actually it's not, I don't know, I don't know him well enough. Erm. But being motivated that actually there is a few hundred steps in between, and it starts with opening your bedroom door to come downstairs, to do the next thing to do the next thing. So like the motivation and direction. But that's probably quite general, not just for girls, erm. And where, yeah... I don't really know, I'm not really saying that very well...
Our, it's been quite helpful for me to understand the kind of social interaction and communication aspects of the field.

In children with Autism, communication is different. It often relies on verbal language. Emotions are often expressed through body language, facial expressions, and eye contact. In addition, children with Autism may have difficulty understanding the social cues of others.

Communication in children with Autism is different - idiosyncratic

Intelligence is different as well. Autistic children can sometimes have strengths in certain areas, such as in reading or math. However, they may struggle with other areas, such as writing or spelling.

Children with Autism typically do not develop normally in the areas of communication and social interaction as well. However, they can improve with proper support and intervention.

The overall goal is to help children with Autism develop the skills they need to function effectively in society.

Coding Density...
Appendix 2F: List of codes from stage 2

- ASD girls have greater social awareness than ASD boys
- ASD boys’ social awareness more variable
- Social awareness → Awareness of difference → Social motivation → Wanting to fit in → mimicking/copying if able
- Gender difference in social responses/ability make gender differences in social awareness hard to judge
- Extend of ASD girls social awareness
- Social awareness means you know you don’t fit in
- Effects of social awareness
- Social awareness pre-requisites
- ASD girls finding social too hard and withdrawing
- Isolation
- Communication and social interaction closely linked and influence each other, but separate
- ASD girls social, at least on the surface
- ASD boys don’t fit in
- ASD boys and ASD girls both struggle in social groups
- Limited differences on social ability between ASD boys and ASD girls
- ASD girls socially better than ASD boys
- ASD girls learning social interaction
- ASD girls masking
- ASD girls copying
- ASD girls copying social interaction/play
- ASD girls copying social communication and language
- ASD girls watch and learn
- ASD boys don’t try to hide
- Some ASD boys can try to copy/mimic/learn social communication and interaction, but more ASD girls do it, and are better at it
- ASD girls watching social TV and learning from it
- Social communication complex and sophisticated, but can be learned
• Social communication/interaction problem key concern to people with ASD and their families
• ASD girls struggle with subtleties of reciprocal, dynamic communication → feels off
• All people with ASD struggle with expressive/receptive verbal/nonverbal communication
• ASD girls’ expressive communication (verbal and non-verbal) ok
• ASD girls verbal and nonverbal communication ok in day to day situations, but cracks under pressure
• ASD girls’ communication generally better than ASD boys
• Social warmth = (gives you) support
• Social warmth linked with sociability/likability/flexibility
• ASD boys and girls seeking out low demand playmates
• ASD girls more controlling
• ASD boys might have mothering female friends
• ASD boys’ friendships (if any) based on games/adult maintained → rules based
• Nature of friendships different between ASD boys and ASD girls
• ASD girls’ friendships can be helpful
• ASD girls having one, sometimes obsessive, friendship
• ASD girls struggling to keep/maintain friendships → often on periphery or falling out
• ASD boys externalising leads to Ax (ASD and other)
• ASD girls internalising
• NT girls internalising, NT boys externalising
• ASD boys having more acting out/externalising behaviours
• ASD boys externalising driven by anxiety/stress/emotional regulation
• ASD girls’ passive in friendships
• ASD girls’ vulnerability worries (clinicians’ worried about vulnerability)
• ASD girls’ passive/cajolable
• (Socialisation + Nature) → Internalising/externalising (which, combined with anxiety) leads to passivity/avoidance
• ASD girls avoid demands
• ASD boys confront/refuse demands
• ALL girls more compliant/perfectionistic/avoiding, ALL boys more refusing/noncompliant/confrontational
• No differences in level of demand avoidance between ASD boys and ASD girls, only in presentation
• Society more accepting/more quirky
• Need to realise ASD different in girls
• ASD boys obvious
• People struggle to understand and remember ASD in girls
• People don’t expect or dismiss ASD in girls
• ASD and NT gender differences in tolerance of difference
• People don’t think ASD for girls
• ASD in boys culturally acceptable
• ASD girls less likely than ASD boys to have early language problems but no difference with older
• ASD girls can struggle with higher order pragmatics
• Similar language ability in ASD boys and ASD girls
• Language difficulties in literality/misinterpreting/echolalia difficult to hide
• Expressive language better than receptive language
• Gender neutral (computer) games popular with ASD boys and ASD girls
• ASD girls appear imaginative on the surface
• ASD girls appear more imaginative than ASD boys
• ASD girls can look imaginative but actually copied/repetitive/scripted/inflexible
• Unsure if play behaviour in ASD gender stereotyped
ASD boys and ASD girls find it equally difficult to change play to fit others

No gender differences in imagination

Imaginative play thought out/copied

ASD boys imaginative play poorer/absent

ASD boys imaginative play requires a premise

ASD girls more exposed to experiences to practice imagination

ASD girls imaginative play superficially ok, developmentally appropriate and present in Hx

ASD girls and empathy

ASD girls’ emotional recognition of others

ASD boys struggle with empathy

ASD boys’ recognition of emotions in others

Classic ASD presentation different to HF ASD

Classic presentations picked up early (Male and Female)

Can hide ASD if average to high IQ

Gender differences at HF not LF end of the spectrum

Gut feeling and “barn door” common and easy in ASD boys

Gut feeling delayed/subtle in ASD girls, but important

Gut feeling about socio-emotional connectedness

Take gut feeling with caution

Autism has many etiologies that create same flavour of presentation

ASD presentation combination of genes and environment

Huge variation within, not just between genders, through multiple routes

Autism is a neurodevelopmental disorder

Social communication part of ASD

Social communication core to ASD

ASD boys and ASD girls present differently

ASD girls more subtle

ASD girls under the radar
• ASD girls’ HF
• ASD girls protected
• ASD boys and ASD girls different but lots of variation in ASD presentation with and between genders
• Genes and gender differences
• Sensory issues
• Sensory issues have an impact
• Sensory issues underrepresented key part of Autism
• ASD girls trying to cope, at a cost
• Cost of coping for people with ASD (mental health)
• ASD girls better able to cope
• ASD girls coping alone
• ASD girls coping with social stuff leads to anxiety
• Cost of coping for ASD girls (Mental Health)
• ASD boys and girls home/school duality
• Impacts of Mental Health on ASD
• ASD and eating disorders
• Boys and girls with ASD are anxious
• Sexuality queries/gender dysphoria
• MH problems more common on girls with ASD
• Effect of bullying
• Girls more emotional skill but more anxiety
• School leading to MH difficulties
• Awareness of difference leads to mental health difficulties
• Rigidity cause of anxiety
• ASD girls and ASD boys talking about emotions
• Therapy modifications for ASD
• ASD girls in therapy have complex/unusual/learned responses
• Engagement in therapy
• ASD girls’ emotional recognition of self
• ASD girls’ emotional regulation and the feeling of emotion
• RRBIs core feature of ASD
• Culture impacts RRBIs
• Girls with ASD present with less RRBIs
• Higher functioning kids can mask RRBIs
• ASD girls’ interests mainstream/common/seen in NT girls/socially acceptable
• ASD girls’ interests not obvious as ASD at first glance
• Japanese culture seen more in ASD girls and less in ASD boys
• ASD girls tending to more creative/cultural interests
• ASD interests incongruent with age
• ASD girls’ interests more social (ASD boys’ interests less social)
• ASD girls interest in mimicking another person can become obsessional
• Computer/systems seen more in ASD boys and less in ASD girls
• ASD girls’ interests intense but not unusual/are socially acceptable
• ASD girls’ interests lacking intensity
• ASD boys interest intense but not unusual/are socially acceptable
• ASD girls can have intensity without specific interest
• ASD girls’ interests pursued with intensity
• Intensity of special interest same for ASD boys and ASD girls
• ASD boys not able to hide interest → Talk more about them
• ASD girls hide interest so don’t talk about them/modulate/hide
• ASD boys’ interests overt
• ASD boys’ interests can be unusual/odd/memorable
• Computer special interests becoming socially acceptable for males
• ASD girls might not have obsessive interest
• Rigidity linked to cognitive, social and anxiety difficulties
• Quality of rigidity different between ASD girls and ASD boys
• ASD girls easier to redirect/better at following others agendas than ASD boys
• ASD boys’ rigidity about repetitive behaviour/rituals/others keeping to standards
• ASD girls’ rigidity around routines/how things should be done/self following standards
• ASD girls more rigid than ASD boys
• ASD girls less rigid than ASD boys
• ASD girls and ASD boys equal in rigidity
• ASD girls’ rigidity can be masked/subtle
• Easier to see rigidity rather than social stuff in ASD girls
• ASD girls using rigid black and white thinking style to understand/work out social stuff
• ASD girls possibly more perfectionistic
• ASD thinking style important feature of ASD
• ASD girls pretending to be animals, ASD boys taking on sci-fi/computer game roles
• ASD girls fantasy worlds could be escapism
• Fantasy worlds impact on social relationships
• Fantasy/reality blurring more an issue for younger kids with ASD
• No gender differences in likelihood of fantasy/reality blurring between ASD boys and ASD girls
• ASD girls more likely to get fantasy/reality blurring than ASD boys
• ASD boys more likely to get fantasy/reality blurring than ASD girls
• Hard for ASD kids to meet High School demands/transitions/complexity
• Greater environmental demands in high school/transition
• Older ASD girls’ presentation
• Younger ASD girls’ presentation
• Younger ASD boys’ presentation
• Older ASD boys’ presentation
• People with ASD not making social developmental jump
• Older HF kids learn to compensate, but can’t keep up (with social development)
• ASD girls’ different social development trajectory
• ASD girls can’t keep up with increase in social complexity in early teenage years
• Social complexity for girls increases in early teenage years
• Effect of clinician on gender
• Observer attributions of gender bias
• We socialise boys and girls differently
• Different expectations for ASD boys and ASD girls
• Huge cultural pressures for ASD and NT girls
• ASD girls more susceptible to culture
• Boys are boisterous/nerdy, girls are empathetic/mean
• Culture provides ASD girls with opportunities and risks
• Boys less fussed about consequences of not engaging
• No gender differences in social drive
• ASD girls social drive lower than NT girls
• ASD girls have social motivation but difficulty acting on it successfully
• ASD girls have higher social motivation/drive/interest than ASD boys
• Fears fuelling ASD girls’ social motivation
• Desires fulling ASD girls’ social motivation
• ASD and NT boys less social interest/ability
• ASD and NT boys’ social behaviour different to ASD and NT girls’ social behaviour
• ASD and NT girls’ social relationships more complex
• ASD and NT girls have greater social ability/drive/awareness/copying/communication
• ASD and NT boys’ social interaction simpler
• Need to question results of structured assessments, including ADOS
• Need to be particularly questioning of evidence when Ax ASD girls
• Informants and indirect info not ideal, and can be wrong/biased
Need to question all evidence informing Ax and investigate discrepancies

ASD overlaps/comorbidities with epilepsy, ADHD, Dyspraxia

Eating disorders can look like ASD → ASD girls miss diagnosed

Lots of things (attachment, LD, etc.) can look like ASD

ASD boys get different labels to ASD girls (ADHD, attachment, behaviour, etc.)

No gender differences in people with ASD getting PD labels

Confirmation bias – once labelled as anxiety cannot be anything else

Professionals prefer to refer girls for Mental Health intervention rather than ASD Ax

Hard to disentangle ASD and Anxiety

ASD girls presenting to Mental Health services with anxiety but underlying ASD not picked up

Clinicians knowing (HF/ASD girls) is going to meet criteria/represent with problems but not able to give dx yet as not meeting criteria

Younger (HF/ASD girls) kids ok on first presentation but meet criteria later when social complexity increases

Dx formulation should be needs focused

Important to consider other dx/is dx needed

Formulating Dx important, especially for ASD girls/complex cases

Formulation is not a tick box “can I explain it this way” exercise

Dx formulation needs to consider environment, developmental opportunities and cultural influences

Dx formulation needs to consider genetics, neurodevelopment and cognitive development

Dx formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans diagnostic categories (internalising/externalising)

ASD girls presenting to mental health services and being missed/discharged
• ASD girls and boys have different routes to Dx
• Accurate at picking up ASD girls in Ax, but still under Dx of girls and more likely to be miss Dxed
• ASD girls coming for Dx later – teenage years. ASD boys coming for Dx in childhood
• Variability in if someone gets Dx due to team or development is not good
• Unsure what good Dx pathway looks like, but involves ability to think more broadly and in-depth if needed
• People coming to Tier 3 getting Dx due to different criteria and able to look at softer symptoms
• Time to get to know someone important in diagnosis
• Pressures for quick, high throughput pathway risks Dx reliability and quality
• MDT important in Ax, especially for ASD girls
• No gender differences in post Dx support offered/uptake (internalising/externalising = different MH support)
• ASD girls more likely to worry about sharing Dx
• Persons perspective on Dx and if they want Dx important
• Dx must be at the right time for the person and their family
• Families prefer Aspergers or PDA dx → Dislike autism label (DSM-5)
• Clinicians having to explain different terminology (PDA, DSM-5) → confusing for families
• Dx not as useful as the support it accesses
• Dx can reduce the persons and their family’s anxiety
• Dx can help the person understand themselves
• Would a Dx be helpful an important consideration
• Dyad useful and step forward
• Different clinicians using triad and/or dyad leads to confusion for families
• Each part of the triad needs to be present at some time in Hx, and have impact on the person for Dx
• Dimensional view of ASD arbitrary but helpful
• Separating social and communication in triad helpful
• Triad is social, communication and RRBIs
• Triad has limits/weaknesses
• Triad of impairments not capturing everything about ASD
• Triad helpful to clinician thinking and easy to explain
• Triad helpful in identifying strengths and weaknesses
• Experience allows clinicians to get to know how ASD girls present
• Clinical experience needed to unpick coping strategies and notice subtler presentations
• Clinical experience allows clinicians to question/overrule measures
• Experience needed when Ax ASD, particularly for girls
• Person can get Dx even when evidence poor/contradictory
• Different professionals can disagree on ASD Dx → variations on experience/expertise?
• Clinical judgement needed particularly for ASD girls
• Clinical judgement can/should overrule measures or Dx criteria
• Professionals anxious about Dxing girls with ASD, especially if complex or just about managing
• Professionals find it hard to think about ASD in girls as used to how boys present → look for other explanations
• Schools (and parents) not picking up ASD girls for Ax, better at ASD boys
• MH professionals need to be aware and think about ASD in the girls they see
• Need to increase awareness of ASD in girls and how to look for it
• ASD girls more likely to show inconstant presentation across environments
• Focus of school observation interaction with peers → ASD girls’ presentation subtle
• Extended observation, in at least one unstructured environment important
• School obs always helpful but particularly for HF ASD girls/borderline cases
• Dx often clearer when you get to know someone over time
• Triad not always visible in Ax → Need to go to Hx/obs to find (RRBIs)
• Hx allows you to see development over time and the environmental/developmental opportunities they had
• Hx important in all ASD Ax but particularly for ASD girls, HF ASD, borderline cases, etc.
• Hx helps you to see behind the mask/clues the mask exists for ASD girls
• Good Hx means you can focus on the behaviour in obs/Ax rather than worrying about what is driving it/DDx
• Males and females with ASD will react differently to male and female assessors
• Informants have gender biases and preconceptions
• Cannot avoid examiner gender bias. What is important is being aware of it and getting multiple perspectives
• Male assessors have lower standards (for social communication and interaction) than female assessors
• Male assessors find it harder to talk about ASD girls’ interests and give less social openings
• Parental report important but might need to prove (but don’t dismiss!)
• Hx, obs, reports from multiple sources needed to get 360-degree view required for Ax (may not need ADOS)
• School/teacher reports of ASD girls require more probing/questioning to pin down ASD behaviours
• Standardised measures important part of Ax → Pinch of salt for ASD girls
• Error of measurement in ADOS/ADI/Measures
• Need to reset NT benchmark on ADOS
• ADOS scoring subject to interpretation → Need to interpret correctly (for girls)
• ADOS 1 piece of the puzzle → cannot base Dx on ADOS alone
• ADOS a tool, not a diagnosis → ASD girls might not score up but still get Dx
• Need to question ADOS scores and understand why they did/did not score
• Discrepancy between ABAS and IQ indicator of possible ASD in HF cases
• ASD boys and older ASD girls most likely to refuse to engage in assessment
• Disagreement over whether ADOS administered-scored differently for ASD boys/ASD girls
• Pre-teen ASD girls not being picked up on ADOS → coming back as teenager and getting Dx
• ASD girls can score up ok on ADOS
• HF ASD girls (and boys) can pass ADOS through subtlety/learning, even if slightly unusual presentation
• ADOS and other measures not sensitive to ASD girls
• HF ASD girls and boys’ language subtle but structured Ax (ADOS) good at finding these
• ASD girls use more and better gesture than ASD boys, but might appear overdramatic/learned
• ADOs might not pick up on learned nature of social communication in ASD girls (Eye contact, Facial expression, etc.)
• ASD boys and average functioning ASD girls caught out on social communication in ADOS
• ASD girls more likely to become “unstuck” on emotion and friendships → need to probe these more
• ASD girls may be able to label emotions in a book but might struggle to talk about them properly → need to tease these out
• ADOS won’t pick up on emotion regulation difficulties, ADI will
• ADOS good, but limited on ability to measure insight/social relationship skill
• ASD girls able to give surface satisfactory answers to insight/social questions on ADOS
• HF ASD girls (and HF boys) less likely to present with RRBIs in ADOS
• ASD girls’ interests fine on ADOS
• ASD girls able to intellectualise through social imagination tasks on ADOS → Need to push (change the story, add complexity)
• RRBIs may not present in Ax → by Hx or on report only
• Have to dig to tempt girls to talk about special interests
• ASD girls (and HF ASD boys) intellectualising through play Ax → Is this imaginative or rehearsed? Are they engaging me correctly?
• Have to work hard to get ASD boys to talk about thoughts
• Need to assess insight (how my actions effect others) → boys parrot, girls only surface understanding
• ASD girls’ friendships/social skills “clincher”
• ASD boys social/friendship difficulties obvious. ASD girls might have better descriptives/motivation
• Sense of reciprocity, of thinking about me correctly in this situation key ASD indicator
• Friendships (starting/maintenance/understanding) important to evaluate when Ax
• HF ASD girls (and HF boys) often have good social communication
• Have to unpick HF ASD girls (and HF boys) social communication → is it learned/mimicked? Use self as a social tool to find out
• ASD girls more likely to chat in Ax → Easy to assume fine. Need to really evaluate/push/challenge to see if true reciprocity
• Language (echolalia/unusual) key indicator for ASD in girls
• ASD boys saying “don’t know” or rehearsed answer to emotion questioning
• ASD girls can do better/pass emotional recognition and understanding tasks
• Have to probe/test emotional understanding in ASD girls (less so in ASD boys)
• Emotional response a key Dx indicator for ASD boys and ASD girls
• ASD fundamentally the same but can present differently in Ax
• Inconsistences over comparison group → compare to ASD peers or to NT peers
• ASD girls (and some HF ASD boys) likely to give surface/learned answers with only 1 or 2 red flags → dig deep and check for real understanding
• ASD boys likely to refuse to answer if don’t know. ASD girls likely to try to answer.
• ASD girls (and some HF ASD boys) don’t present in a typical ASD way → Making and know what to do and say to pass assessment
• Have to work harder to unravel ASD girls masking → would be same as boys if they didn’t mask
• ASD boys easier to dx, ASD girls harder to dx
• Ax process and what you are looking for same for ASD boys and ASD girls, BUT presentation and thinking around Ax may differ
• Core difficulties of ASD the same, but people might not tick every box, or do so at the same time/in the same environment
• HF kids not scoring up on social/communication bit of the dx criteria
• HF kids not scoring up on RRBI bit of criteria
• HF (particularly girls) kids with ASD presentation not always captured/Dxed by criteria
• Classically autistic girls easy to meet criteria, harder for HF girls
• ASD girls not being scored up on RRBI criteria
• DX criteria doesn’t fit well for ASD girls
• ASD girls trying socially/ASD boys not trying socially means harder for ASD girls/easier for ASD boys to meet criteria
• DX criteria based on ASD boys so easier for ASD boys/harder for ASD girls to meet criteria
• ASD girls have the same core difficulties, meet the same criteria, but do so differently/more softly
• Experienced clinicians don’t use Dx criteria as a tick box exercise
• Risk of miss/under Dx if use criteria as a tick box exercise
• ASD defined by Dx criteria behaviourally
• Dx criteria based on social, communication and RRBIs
• Dx criteria missing things \(\rightarrow\) anxiety, thinking, executive functioning
• DX criteria can miss diagnose
• Under Dx of ASD girls
• PDA sometimes (but not always) meeting ASD dx criteria
• Dx criteria not as good as a formulation (longevity, functioning, support, etc.)
• Clinical judgement needed to apply/interpret/overrule Dx criteria
• No clear line between NT and ASD
• Criteria pick and mix \(\rightarrow\) lots of sufficient but not all necessary/equal
• DX criteria “loose” and subject to interpretation
• Dx criteria useful as a framework/guide to thinking
• DSM-5 better and preferred
• DSM-5 more flexible, takes a dimensional view and looks more at longevity and impact
• DSM-4/ICD-10 has a narrow, classical, rigid view of ASD
• People with Autism see and react to the world differently
• ASD girls feeling sense of injustice against them
• ASD girls “in their own heads”
• Motivation a difficulty in ASD, linked to imagination
• Diachronic thinking/planning a difficulty in ASD
• Rigidity not part of Autism?
• NT girls more reflective than NT boys
• SD girls, particularly pre-teen hard to pick up for Ax
• Social impairment core to ASD
• Separating criteria into male and female criteria a bad idea
• ASD kids picked up due to difficulties at PS→HS transition
• ASD girls older when picked up for Dx
• ASD girls picked up for Dx later than ASD boys
• ASD boys picked up young due to behaviour → ASD Ax
• ASD girls under Dxed
• ASD girls misdiagnosis
• ASD girls diagnostic overshadowing
• ASD boys alt Dx
• ASD girls picked up due to mental health
Appendix 2G: Starter themes and codes generated by all authors at stage 3

**ASD Girls generally greater social awareness**

ASD girls have greater social awareness than ASD boys

ASD boys’ social awareness more variable

Social awareness → Awareness of difference → Social motivation → Wanting to fit in → mimicking/copying if able

Gender difference in social responses/ability make gender differences in social awareness hard to judge

Extend of ASD girls social awareness

Social awareness means you know you don’t fit in

Effects of social awareness

Social awareness pre-requisites

**ASD girls possibly better social ability, at least on the surface**

ASD girls finding social too hard and withdrawing

Isolation

Communication and social interaction closely linked and influence each other, but separate

ASD girls social, at least on the surface

ASD boys don’t fit in

ASD boys and ASD girls both struggle in social groups

Limited differences on social ability between ASD boys and ASD girls

ASD girls socially better than ASD boys
**ASD girls watch, copy and learn social interaction/communication/emotions**

ASD girls learning social interaction

ASD girls masking

ASD girls copying

ASD girls copying social interaction/play

ASD girls copying social communication and language

ASD girls watch and learn

ASD boys don’t try to hide

Some ASD boys can try to copy/mimic/learn social communication and interaction, but more ASD girls do it, and are better at it

ASD girls watching social TV and learning from it

**ASD girls generally better surface communication but limited in depth**

Social communication complex and sophisticated, but can be learned

Social communication/interaction problem key concern to people with ASD and their families

ASD girls struggle with subtleties of reciprocal, dynamic communication → feels off

All people with ASD struggle with expressive/receptive verbal/nonverbal communication

ASD girls’ expressive communication (verbal and non-verbal) ok

ASD girls verbal and nonverbal communication ok in day to day situations, but cracks under pressure

ASD girls’ communication generally better than ASD boys
Social warmth

Social warmth = (gives you) support

Social warmth linked with sociability/likability/flexibility

Friendships

ASD boys and girls seeking out low demand playmates

ASD girls more controlling

ASD boys might have mothering female friends

ASD boys’ friendships (if any) based on games/adult maintained \( \rightarrow \) rules based

Nature of friendships different between ASD boys and ASD girls

ASD girls’ friendships can be helpful

ASD girls having one, sometimes obsessive, friendship

ASD girls struggling to keep/maintain friendships \( \rightarrow \) often on periphery or falling out

ASD boys externalise, ASD girls internalise

ASD boys externalising leads to Ax (ASD and other)

ASD girls internalising

NT girls internalising, NT boys externalising

ASD boys having more acting out/externalising behaviours

ASD boys externalising driven by anxiety/stress/emotional regulation
ASD boys confront, ASD girls avoid/go away

ASD girls’ passive in friendships

ASD girls’ vulnerability worries (clinicians’ worried about vulnerability)

ASD girls’ passive/cajolable

(Socialisation + Nature) → Internalising/externalising (which, combined with anxiety) leads to passivity/avoidance

ASD girls avoid demands

ASD boys confront/refuse demands

ALL girls more compliant/perfectionistic/avoiding, ALL boys more refusing/noncompliant/confrontational

No differences in level of demand avoidance between ASD boys and ASD girls, only in presentation

Society views on boys’ vs girls with ASD

Society more accepting/more quirky

Need to realise ASD different in girls

ASD boys obvious

People struggle to understand and remember ASD in girls

People don’t expect or dismiss ASD in girls

ASD and NT gender differences in tolerance of difference

People don’t think ASD for girls

ASD in boys culturally acceptable

Limited gender differences in language
ASD girls less likely than ASD boys to have early language problems but no difference with older

ASD girls can struggle with higher order pragmatics

Similar language ability in ASD boys and ASD girls

Language difficulties in literality/misinterpreting/echolalia difficult to hide

Expressive language better than receptive language

**Play and imagination**

Gender neutral (computer) games popular with ASD boys and ASD girls

ASD girls appear imaginative on the surface

ASD girls appear more imaginative than ASD boys

ASD girls can look imaginative but actually copied/repetitive/scripted/inflexible

Unsure if play behaviour in ASD gender stereotyped

**ASD girls better at imaginative play than ASD boys**

ASD boys and ASD girls find it equally difficult to change play to fit others

No gender differences in imagination

Imaginative play thought out/copied

ASD boys imaginative play poorer/absent

ASD boys imaginative play requires a premise

ASD girls more exposed to experiences to practice imagination

ASD girls imaginative play superficially ok, developmentally appropriate and present in Hx
ASD girls better at emotional recognition and empathy with others (compared to boys)

ASD girls and empathy
ASD girls’ emotional recognition of others
ASD boys struggle with empathy
ASD boys’ recognition of emotions in others

Effect of IQ on ASD presentation

Classic ASD presentation different to HF ASD
Classic presentations picked up early (Male and Female)
Can hide ASD if average to high IQ
Gender differences at HF not LF end of the spectrum

Gut feeling

Gut feeling and “barn door” common and easy in ASD boys
Gut feeling delayed/subtle in ASD girls, but important
Gut feeling about socio-emotional connectedness
Take gut feeling with caution

What is Autism?

Autism has many etiologies that create same flavour of presentation
ASD presentation combination of genes and environment
Huge variation within, not just between genders, through multiple routes
Autism is a neurodevelopmental disorder
Social communication part of ASD
Social communication core to ASD

**Broad ASD gender presentation**

ASD boys and ASD girls present differently
ASD girls more subtle
ASD girls under the radar
ASD girls’ HF
ASD girls protected
ASD boys and ASD girls different but lots of variation in ASD presentation with and between genders
Genes and gender differences

**Sensory issues**

Sensory issues
Sensory issues have an impact
Sensory issues underrepresented key part of Autism

**Copying**

ASD girls trying to cope, at a cost
Cost of coping for people with ASD (mental health)
ASD girls better able to cope
ASD girls coping alone
ASD girls coping with social stuff leads to anxiety
Cost of coping for ASD girls (Mental Health)

**Mental Health and ASD**

ASD boys and girls home/school duality

Impacts of Mental Health on ASD

ASD and eating disorders

Boys and girls with ASD are anxious

Sexuality queries/gender dysphoria

MH problems more common on girls with ASD

**Causes of anxiety/Mental health problems for people with ASD**

Effect of bullying

Girls more emotional skill but more anxiety

School leading to MH difficulties

Awareness of difference leads to mental health difficulties

Rigidity cause of anxiety

**Therapy**

ASD girls and ASD boys talking about emotions

Therapy modifications for ASD

ASD girls in therapy have complex/unusual/learned responses

Engagement in therapy

ASD girls’ emotional recognition of self

ASD girls’ emotional regulation and the feeling of emotion
Broad RRBI picture
RRBIs core feature of ASD
Culture impacts RRBIs
Girls with ASD present with less RRBIs
Higher functioning kids can mask RRBIs

Special interests
ASD girls’ interests mainstream/common/seen in NT girls/socially acceptable
ASD girls’ interests not obvious as ASD at first glance
Japanese culture seen more in ASD girls and less in ASD boys
ASD girls tending to more creative/cultural interests
ASD interests incongruent with age
ASD girls’ interests more social (ASD boys’ interests less social)
ASD girls interest in mimicking another person can become obsessional
Computer/systems seen more in ASD boys and less in ASD girls
ASD girls’ interests intense but not unusual/are socially acceptable
ASD girls’ interests lacking intensity
ASD boys interest intense but not unusual/are socially acceptable
ASD girls can have intensity without specific interest
ASD girls’ interests pursued with intensity
Intensity of special interest same for ASD boys and ASD girls
ASD boys not able to hide interest → Talk more about them
ASD girls hide interest so don’t talk about them/modulate/hide
ASD boys’ interests overt

ASD boys’ interests can be unusual/odd/memorable

Computer special interests becoming socially acceptable for males

ASD girls might not have obsessive interest

**Rigidity**

Rigidity linked to cognitive, social and anxiety difficulties

Quality of rigidity different between ASD girls and ASD boys

ASD girls easier to redirect/better at following others agendas than ASD boys

ASD boys’ rigidity about repetitive behaviour/rituals/others keeping to standards

ASD girls’ rigidity around routines/how things should be done/self following standards

ASD girls more rigid than ASD boys

ASD girls less rigid than ASD boys

ASD girls and ASD boys equal in rigidity

ASD girls’ rigidity can be masked/subtle

Easier to see rigidity rather than social stuff in ASD girls

ASD girls using rigid black and white thinking style to understand/work out social stuff

ASD girls possibly more perfectionistic

ASD thinking style important feature of ASD
Fantasy/reality blurring

ASD girls pretending to be animals, ASD boys taking on sci-fi/computer game roles

ASD girls fantasy worlds could be escapism

Fantasy worlds impact on social relationships

Fantasy/reality blurring more an issue for younger kids with ASD

No gender differences in likelihood of fantasy/reality blurring between ASD boys and ASD girls

ASD girls more likely to get fantasy/reality blurring than ASD boys

ASD boys more likely to get fantasy/reality blurring than ASD girls

School transition

Hard for ASD kids to meet High School demands/transitions/complexity

Greater environmental demands in high school/transition

Older vs younger presentation of ASD in boys and girls

Older ASD girls’ presentation

Younger ASD girls' presentation

Younger ASD boys' presentation

Older ASD boys’ presentation

Social developmental demand jumps

People with ASD not making social developmental jump

Older HF kids learn to compensate, but can’t keep up (with social development)
ASD girls’ different social development trajectory

ASD girls can’t keep up with increase in social complexity in early teenage years

Social complexity for girls increases in early teenage years

**Differential effect of culture on gender**

Effect of clinician on gender

Observer attributions of gender bias

We socialise boys and girls differently

Different expectations for ASD boys and ASD girls

Huge cultural pressures for ASD and NT girls

ASD girls more susceptible to culture

Boys are boisterous/nerdy, girls are empathetic/mean

Culture provides ASD girls with opportunities and risks

**ASD girls more socially motivated**

Boys less fussed about consequences of not engaging

No gender differences in social drive

ASD girls social drive lower than NT girls

ASD girls have social motivation but difficulty acting on it successfully

ASD girls have higher social motivation/drive/interest than ASD boys

Fears fuelling ASD girls’ social motivation

Desires fuelling ASD girls’ social motivation
Boys social interaction simple and have less ability, girls more social and interaction more complex, with more social ability

ASD and NT boys less social interest/ability

ASD and NT boys’ social behaviour different to ASD and NT girls’ social behaviour

ASD and NT girls’ social relationships more complex

ASD and NT girls have greater social ability/drive/awareness-copying/communication

ASD and NT boys’ social interaction simpler

Questioning evidence

Need to question results of structured assessments, including ADOS

Need to be particularly questioning of evidence when Ax ASD girls

Informants and indirect info not ideal, and can be wrong/biased

Need to question all evidence informing Ax and investigate discrepancies

Misdiagnosis

ASD overlaps/comorbidities with epilepsy, ADHD, Dyspraxia

Eating disorders can look like ASD → ASD girls miss diagnosed

Lots of things (attachment, LD, etc.) can look like ASD

ASD boys get different labels to ASD girls (ADHD, attachment, behaviour, etc.)

No gender differences in people with ASD getting PD labels

Confirmation bias – once labelled as anxiety cannot be anything else

Professionals prefer to refer girls for Mental Health intervention rather than ASD Ax
Hard to disentangle ASD and Anxiety

ASD girls presenting to Mental Health services with anxiety but underlying ASD not picked up

**DX criteria not covering all ages equally**

Clinicians knowing (HF/ASD girls) is going to meet criteria/represent with problems but not able to give dx yet as not meeting criteria

Younger (HF/ASD girls) kids ok on first presentation but meet criteria later when social complexity increases

**Formulating a Dx**

Dx formulation should be needs focused

Important to consider other dx/is dx needed

Formulating Dx important, especially for ASD girls/complex cases

Formulation is not a tick box “can I explain it this way” exercise

Dx formulation needs to consider environment, developmental opportunities and cultural influences

Dx formulation needs to consider genetics, neurodevelopment and cognitive development

Dx formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans diagnostic categories (internalising/externalising)

**Gender differences on diagnostic routes**

ASD girls presenting to mental health services and being missed/discharged

ASD girls and boys have different routes to Dx
Accurate at picking up ASD girls in Ax, but still under Dx of girls and more likely to be miss Dxed

ASD girls coming for Dx later – teenage years. ASD boys coming for Dx in childhood

**Pathway design**

Variability in if someone gets Dx due to team or development is not good

Unsure what good Dx pathway looks like, but involves ability to think more broadly and in-depth if needed

People coming to Tier 3 getting Dx due to different criteria and able to look at softer symptoms

Time to get to know someone important in diagnosis

Pressures for quick, high throughput pathway risks Dx reliability and quality

MDT important in Ax, especially for ASD girls

**Post Dx Support**

No gender differences in post Dx support offered/uptake  
(internalising/externalising = different MH support)

ASD girls more likely to worry about sharing Dx

**Considerations when giving Dx**

Persons perspective on Dx and if they want Dx important

Dx must be at the right time for the person and their family

Families prefer Aspergers or PDA dx → Dislike autism label (DSM-5)

Clinicians having to explain different terminology (PDA, DSM-5) → confusing for families
Value of a diagnosis
Dx not as useful as the support it accesses
Dx can reduce the persons and their family’s anxiety
Dx can help the person understand themselves
Would a Dx be helpful an important consideration

Triad of impairments
Dyad useful and step forward
Different clinicians using triad and/or dyad leads to confusion for families
Each part of the triad needs to be present at some time in Hx, and have impact on the person for Dx
Dimensional view of ASD arbitrary but helpful
Separating social and communication in triad helpful
Triad is social, communication and RRBIs
Triad has limits/weaknesses
Triad of impairments not capturing everything about ASD
Triad helpful to clinician thinking and easy to explain
Triad helpful in identifying strengths and weaknesses

Professional experience in ASD Ax
Experience allows clinicians to get to know how ASD girls present
Clinical experience needed to unpick coping strategies and notice subtler presentations
Clinical experience allows clinicians to question/overrule measures

Experience needed when Ax ASD, particularly for girls

**Professional judgement in ASD Ax**

Person can get Dx even when evidence poor/contradictory

Different professionals can disagree on ASD Dx → variations on experience/expertise?

Clinical judgement needed particularly for ASD girls

Clinical judgement can/should overrule measures or Dx criteria

**Lack of awareness stops ASD girls being assessed**

Professionals anxious about Dxing girls with ASD, especially if complex or just about managing

Professionals find it hard to think about ASD in girls as used to how boys present → look for other explanations

Schools (and parents) not picking up ASD girls for Ax, better at ASD boys

MH professionals need to be aware and think about ASD in the girls they see

Need to increase awareness of ASD in girls and how to look for it

**Observation**

ASD girls more likely to show inconstant presentation across environments

Focus of school observation interaction with peers → ASD girls’ presentation subtle

Extended observation, in at least one unstructured environment important

School obs always helpful but particularly for HF ASD girls/borderline cases
**Hx**

Dx often clearer when you get to know someone over time

Triad not always visible in Ax → Need to go to Hx/obs to find (RRBIs)

Hx allows you to see development over time and the environmental/developmental opportunities they had

Hx important in all ASD Ax but particularly for ASD girls, HF ASD, borderline cases, etc.

Hx helps you to see behind the mask/clues the mask exists for ASD girls

Good Hx means you can focus on the behaviour in obs/Ax rather than worrying about what is driving it/DDx

**Gender bias in assessment process**

Males and females with ASD will react differently to male and female assessors

Informants have gender biases and preconceptions

Cannot avoid examiner gender bias. What is important is being aware of it and getting multiple perspectives

Male assessors have lower standards (for social communication and interaction) than female assessors

Male assessors find it harder to talk about ASD girls’ interests and give less social openings

**360-degree view**

Parental report important but might need to prove (but don’t dismiss!)

Hx, obs, reports from multiple sources needed to get 360-degree view required for Ax (may not need ADOS)
School/teacher reports of ASD girls require more probing/questioning to pin down ASD behaviours

**Use and questioning of standardised measures**

Standardised measures important part of Ax → Pinch of salt for ASD girls

Error of measurement in ADOS/ADI/Measures

Need to reset NT benchmark on ADOS

ADOS scoring subject to interpretation → Need to interpret correctly (for girls)

ADOS 1 piece of the puzzle → cannot base Dx on ADOS alone

ADOS a tool, not a diagnosis → ASD girls might not score up but still get Dx

Need to question ADOS scores and understand why they did/did not score

Discrepancy between ABAS and IQ indicator of possible ASD in HF cases

**Gender differences in ADOS and other measures**

ASD boys and older ASD girls most likely to refuse to engage in assessment

Disagreement over whether ADOS administered/scored differently for ASD boys/ASD girls

Pre-teen ASD girls not being picked up on ADOS → coming back as teenager and getting Dx

ADOS girls can score up ok on ADOS

HF ASD girls (and boys) can pass ADOS through subtlety/learning, even if slightly unusual presentation

ADOS and other measures not sensitive to ASD girls
ADOS social communication

HF ASD girls and boys’ language subtle but structured Ax (ADOS) good at finding these

ASD girls use more and better gesture than ASD boys, but might appear overdramatic/learned

ADoS might not pick up on learned nature of social communication in ASD girls (Eye contact, Facial expression, etc.))

ADOS boys and average functioning ASD girls caught out on social communication in ADOS

ADOS social-emotional

ASD girls more likely to become “unstuck” on emotion and friendships → need to probe these more

ASD girls may be able to label emotions in a book but might struggle to talk about them properly → need to tease these out

ADOS won’t pick up on emotion regulation difficulties, ADI will

ADOS good, but limited on ability to measure insight/social relationship skill

ASD girls able to give surface satisfactory answers to insight/social questions on ADOS

ADOS RRBIs

HF ASD girls (and HF boys) less likely to present with RRBIs in ADOS

ASD girls’ interests fine on ADOS

ASD girls able to intellectualise through social imagination tasks on ADOS → Need to push (change the story, add complexity)
**ASD Ax → RRBIs and play**

RRBIs may not present in Ax → by Hx or on report only

Have to dig to tempt girls to talk about special interests

ASD girls (and HF ASD boys) intellectualising through play Ax → Is this imaginative or rehearsed? Are they engaging me correctly?

Have to work hard to get ASD boys to talk about thoughts

**ASD Ax → Friendships/insight**

Need to assess insight (how my actions effect others) → boys parrot, girls only surface understanding

ASD girls’ friendships/social skills “clincher”

ASD boys social/friendship difficulties obvious. ASD girls might have better descriptives/motivation

Sense of reciprocity, of thinking about me correctly in this situation key ASD indicator

Friendships (starting/maintenance/understanding) important to evaluate when Ax

**ASD Ax → Social communication**

HF ASD girls (and HF boys) often have good social communication

Have to unpick HF ASD girls (and HF boys) social communication → is it learned/mimicked? Use self as a social tool to find out

ASD girls more likely to chat in Ax → Easy to assume fine. Need to really evaluate/push/challenge to see if true reciprocity

Language (echolalia/unusual) key indicator for ASD in girls
**ASD Ax → Emotions**

ASD boys saying “don’t know” or rehearsed answer to emotion questioning

ASD girls can do better/pass emotional recognition and understanding tasks

Have to probe/test emotional understanding in ASD girls (less so in ASD boys)

Emotional response a key Dx indicator for ASD boys and ASD girls

**Broad gender differences in assessment**

ASD fundamentally the same but can present differently in Ax

Inconsistencies over comparison group → compare to ASD peers or to NT peers

ASD girls (and some HF ASD boys) likely to give surface/learned answers with only 1 or 2 red flags → dig deep and check for real understanding

ASD boys likely to refuse to answer if don’t know. ASD girls likely to try to answer.

ASD girls (and some HF ASD boys) don’t present in a typical ASD way → Making and know what to do and say to pass assessment

Have to work harder to unravel ASD girls masking → would be same as boys if they didn’t mask

ASD boys easier to dx, ASD girls harder to dx

Ax process and what you are looking for same for ASD boys and ASD girls, BUT presentation and thinking around Ax may differ

**HF ASD kids don’t score up well on Dx Criteria**

Core difficulties of ASD the same, but people might not tick every box, or do so at the same time/in the same environment

HF kids not scoring up on social/communication bit of the dx criteria
HF kids not scoring up on RRBI bit of criteria

HF (particularly girls) kids with ASD presentation not always captured/Dxed by criteria

Classically autistic girls easy to meet criteria, harder for HF girls

(HF) ASD girls don’t score up well on Dx criteria

ASD girls not being scored up on RRBI criteria

Dx criteria doesn’t fit well for ASD girls

ASD girls trying socially/ASD boys not trying socially means harder for ASD girls/easier for ASD boys to meet criteria

Dx criteria based on ASD boys so easier for ASD boys/harder for ASD girls to meet criteria

ASD girls have the same core difficulties, meet the same criteria, but do so differently/more softly

Don’t use criteria as a tick box exercise

Experienced clinicians don’t use Dx criteria as a tick box exercise

Risk of miss/under Dx if use criteria as a tick box exercise

Nature of criteria

ASD defined by Dx criteria behaviourally

Dx criteria based on social, communication and RRBI

Flaws in criteria

Dx criteria missing things → anxiety, thinking, executive functioning
DX criteria can miss diagnose
Under Dx of ASD girls
PDA sometimes (but not always) meeting ASD dx criteria

Criteria a guide but need clinical judgement/formulation
Dx criteria not as good as a formulation (longevity, functioning, support, etc.)
Clinical judgement needed to apply/interpret/overrule Dx criteria
No clear line between NT and ASD
Criteria pick and mix → lots of sufficient but not all necessary/equal
DX criteria “loose” and subject to interpretation
Dx criteria useful as a framework/guide to thinking

DSM-4 Vs DSM-5 Vs ICD-10
DSM-5 better and preferred
DSM-5 more flexible, takes a dimensional view and looks more at longevity and impact
DSM-4/ICD-10 has a narrow, classical, rigid view of ASD

Uncategorised
People with Autism see and react to the world differently
ASD girls feeling sense of injustice against them
ASD girls “in their own heads”
Motivation a difficulty in ASD, linked to imagination
Diachronic thinking/planning a difficulty in ASD
Rigidity not part of Autism?

NT girls more reflective than NT boys

ASD girls, particularly pre-teen hard to pick up for Ax

Social impairment core to ASD

Separating criteria into male and female criteria a bad idea

ASD kids picked up due to difficulties at PS→HS transition

ASD girls older when picked up for Dx

ASD girls picked up for Dx later than ASD boys

ASD boys picked up young due to behaviour → ASD Ax

ASD girls under Dxed

ASD girls misdiagnosis

ASD girls diagnostic overshadowing

ASD boys alt Dx

ASD girls picked up due to Mental Health
Appendix 2H: New codes created from miscellaneous descriptors from stage 4

Number in (brackets) indicates number of descriptors in a code

- ASD girls special interest providing an identity/role (1)
- ASD boys interests more about having, ASD girls interests more about doing (1)
- Diagnostic criteria fine for most children (2)
- Imagination more than making up stories (2)
- ASD boys happier spending time on special interests and becoming proficient (2)
- Boys and girls with ASD can have obsessive interests (2)
- Friendships are hard for people with autism (2)
- Risk of small number of ASD girls and confirmation bias on my own research (2)
- Our view of autism, it's name, and it's features have changed over time and will continue to change (2)
- Circularity compromising existing evidence base (3)
- Female professionals delivering social/communication based intervention; is this meeting the needs of predominantly male clients? (3)
- People with autism acting younger or older than their chronological age (4)
- Potential for intervention in autism in the near future (social communication) (5)
- Autism is not a “ghost in the machine” (5)
- Our understanding of child development and what is normal has changed over time an in tandem with cultural changes (many)
Appendix 2I: Discarded descriptors from stage 4

- ASD need for control and not going to school overrides any perfectionism about school work or grades
- ASD boy may not like changes or violations of school rules, but ASD girl will become passionate about them
- ASD need for control over not going to school
- ASD presentation can be framed in terms of challenging behaviour
- Professionals can think ASD is just behavioural difficulties early on
- Age can effect perceptions of what is socially or culturally appropriate
- Undxed ASD girls often out of schools
- (participant) clinician not researcher
- Aspergers normally has normal language development – not requirement
- Not all play behaviour in ASD is gender stereotyped – some can go against that
- Trans Dx traits broader than internalising externalising – rigidity, social skill, etc
- Important to look at autism from a neuroscience view, not psychiatric criterion based view
- Value in not using tick boxes when assigning gender to people
- Contradiction in information (from participant)
- Language is now a measure of severity, related but separate to core aspect of how a child relates to the world
- Sub dimensions of the two big dimensions (in dx criteria) can exist in the general population
- Is social skills building a mental health thing for psychologists – may help reduce anxiety in the future, but arguably not part of role at the moment
- ASD girls generalise better than ASD boys
- Passivity a passive behaviour, avoidant is active
- People with high functioning autism aware of their feelings, but struggle with others feelings
- Can define ASD in terms of positive and negative symptoms
- People with Aspergers have normal language
- Girls with ASD say dad in particular doesn’t get them
- Mums acting as a translation or communication tool for some ASD girls
- ASD boys can be verbal and unreciprocal in presentation, but less common
- Rigidity and RRBIs could be a neurodevelopmental trait or coping strategy – a primary or secondary difficulty. Unsure which
- HF adults with ASD who are successful can be flexible in thoughts, but they may not have started there
- Despite social adaptation, making home adapt to her (girl with ASD)
- Lack of responsibility common to ASD boys and ASD girls
- ASD girls social ability linked to coping at school
- Girls with ASD say parents don’t get them
- ASD need to learn manifests in special interest keeping them up all night, rather than going into school against their need for control
- Attention to detail is linked to social skill
- Other half of dyad RRBIs, sensory, motor
- Autism can be impairing
- Avoidant behaviour part of ASD
- People with autism have strengths
- NT children know the difference between fantasy and reality, ASD imagination can blur this
- Dx decision in girls – post assessment questions allowed and useful
- If a child is labelled as anxious, they might get less scaffolding, and less likely to get intervention or ax
- ASD boys more likely to ‘talk nonsense’ or confabulate, but not fantasy/reality problem
- Risk of children being ‘storied’ – preconception of autism, so every behaviour and problem is seen through ASD lens
- Important to consider what is underlying behaviour when assessing girls, not just surface behaviour
- For dx, important to have understanding of autism, access to good quality information, and know the difference between conventions vs actual evidence and neuroscience
- ADOS able to discriminate between ASD and trauma
- Dx easier to give than remove – case for waiting and seeing
- ASD boys and girls social response to ADOS qs on social relationships likely to be dictated by response strategy – internalising or externalising.
- ASD girls may get anxious or talk too much
- Will use mental health questionnaires with boys presenting with mental health problems, but more girls presenting with mental health problems so they get more questionnaires
- Something happening causing huge chain of events causing anxiety characteristic of autism
- Risk we may scaffold kids we think of as anxious more than kids we think of as idocyncratic.
Appendix 2J: Full model generated at stage 5

Due to the complexity of this model, it is not possible to adequately reproduce it in paper format. A PDF of this model can be found at www.tinyurl.com/JMThesis, and opened using the password “Wing1979”

Note that themes are indicated by **bold**.

A partial reproduction of the model is on the following 21 pages.

This model consists of twelve superordinate themes. Eleven of these are reproduced below in no particular order. The remaining superordinate theme “**making a diagnostic decision**” is too big to reproduce on paper. It is split into one orientating model, presented first, followed by eight smaller models, each originating from a node on the orientating model. These smaller models can be identified by their single colour, as opposed to the multicolour models which show a superordinate theme.

The following pages also lack inter-theme secondary conceptual links, shown in purple on the PDF version, but do show some intra-theme secondary conceptual links.
Gender differences in superficial social communication, but limited gender differences in language when older. ASD girls less likely than ASD boys to have early language problems but no difference when older. Similar language ability in ASD boys and ASD girls. ASD girls can struggle with higher order pragmatics. ASD girls struggle with the subtleties of reciprocal, dynamic communication, and can feel ‘off’ when interacting with them.

Girls with autism tending to have better surface social communication skills. ASD girls verbal and nonverbal communication ok in day to day situations, but cracks under pressure. ASD girls’ communication generally better than ASD boys.

ASD girls’ expressive communication (verbal and non-verbal) ok. Social communication complex and sophisticated, but can be learned. Girls with autism struggling with more complex communication. ASD girls can struggle with higher order pragmatics.
Girls with autism tend to have more social awareness, have more social motivation, and therefore tend to copy social interaction and communication.

Variations in social awareness and insight among people with autism

ASD boys' social awareness more variable
Gender differences in social responsiveness make gender differences in social awareness harder to judge
ASD girls have greater social awareness than ASD boys

ASD girls have greater social awareness than ASD boys

The social awareness of girls with autism is still limited, and can leave them vulnerable
Clinicians have particular worries about the vulnerability of ASD girls
Extent of ASD girls social awareness

Insight helps you ask for help
Social awareness requires cognitive ability and observation skills

Girls with autism copy social interaction and communication

ASD girls watching and learn
ASD girls watching social TV and learning to fit in
ASD girls watching social interaction

Some ASD boys can try to copy/mimic/learn social communication and interaction, but many ASD girls do it and are better at it.

ASD girls copying social interaction/play
ASD boys don't try to hide
ASD girls masking

ASD girls have higher social motivation than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls' desire to fit in, be part of groups, have friends and relationships driving social motivation
ASD girls learn not to fit in, seeing or doing the wrong thing, not having or identify as part of a group, losing connections, etc.

ASD girls copy social interaction/play

Social connectedness and identity key motivator for the desire to fit in among girls with autism

Girls with Autism tend to have better social awareness

ASD girls have greater social awareness than ASD boys

ASD girls more socially motivated than boys with autism
ASD girls have higher social motivation/drive/interest than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls copying social interaction/play

Some ASD boys can try to copy/mimic/learn social communication and interaction, but many ASD girls do it, and are better at it.

ASD girls copying social communication and language
ASD girls watching social TV
ASD girls learning from watching social TV and interaction

ASD girls watching and learn
ASD girls watching social TV and learning to fit in
ASD girls watching social interaction

Some ASD boys can try to copy/mimic/learn social communication and interaction, but many ASD girls do it and are better at it.

ASD girls copying social interaction/play
ASD boys don't try to hide
ASD girls masking

ASD girls have higher social motivation than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls' desire to fit in, be part of groups, have friends and relationships driving social motivation
ASD girls learn not to fit in, seeing or doing the wrong thing, not having or identify as part of a group, losing connections, etc.

ASD girls copying social interaction/play

Social connectedness and identity key motivator for the desire to fit in among girls with autism

Girls with Autism tend to have better social awareness

ASD girls have greater social awareness than ASD boys

ASD girls more socially motivated than boys with autism
ASD girls have higher social motivation/drive/interest than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls' desire to fit in, be part of groups, have friends and relationships driving social motivation
ASD girls learn not to fit in, seeing or doing the wrong thing, not having or identify as part of a group, losing connections, etc.

ASD girls copying social interaction/play

Social connectedness and identity key motivator for the desire to fit in among girls with autism

Girls with Autism tend to have better social awareness

ASD girls have greater social awareness than ASD boys

ASD girls more socially motivated than boys with autism
ASD girls have higher social motivation/drive/interest than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls' desire to fit in, be part of groups, have friends and relationships driving social motivation
ASD girls learn not to fit in, seeing or doing the wrong thing, not having or identify as part of a group, losing connections, etc.

ASD girls copying social interaction/play

Social connectedness and identity key motivator for the desire to fit in among girls with autism

Girls with Autism tend to have better social awareness

ASD girls have greater social awareness than ASD boys

ASD girls more socially motivated than boys with autism
ASD girls have higher social motivation/drive/interest than ASD boys
No gender differences in social drive in ASD
ASD girls have social motivation but difficulty acting on it successfully
ASD girls social drive lower than NT girls
ASD girls less worried about consequences of not engaging

ASD girls' desire to fit in, be part of groups, have friends and relationships driving social motivation
ASD girls learn not to fit in, seeing or doing the wrong thing, not having or identify as part of a group, losing connections, etc.
Girls with autism hiding special interests, boys can’t hide special interests

ASD boys’ interests overt
ASD girls hide interest so don’t talk about them/modulate/hide

ASD interests incongruent with age

Girls with autism hiding special interests, boys can’t hide special interests

ASD boys are not able to hide their interests, and end up talking about them

ASD girls’ interests not obvious as ASD at first glance
ASD girls’ interests intense but not unusual/are socially acceptable

ASD girls’ interests not obvious as ASD at first glance
ASD girls’ interests intense but not unusual/are socially acceptable

ASD girls’ interests pursued with intensity
ASD girls’ interests lacking intensity

Contradictions among participants over the intensity of special interests in boys and girls

ASD girls can have intensity without specific interest
ASD girls might not have intense special interests

ASD girls’ interests pursued with intensity
ASD girls’ interests lacking intensity

Contradictions among participants over the intensity of special interests in boys and girls

ASD girls can have intensity without specific interest
ASD girls might not have intense special interests

Social acceptability of interests in girls and boys with autism

ASD boys’ interesting can be unusual/odd/memorable
ASD boys’ interests intense but not unusual/are social acceptable

Social acceptability of interests in girls and boys with autism

ASD boys’ interesting can be unusual/odd/memorable
ASD boys’ interests intense but not unusual/are social acceptable

Interests of girls and boys with autism differ

ASD boys and girls’ interest pursue with intensity
ASD girls’ interests lacking intensity

Intensity of special interest same for ASD boys and ASD girls

Interests of girls and boys with autism often have a social or cultural focus

ASD girls’ interest more social
ASD boys’ interests less social

Interests of boys with autism often unusual, but increasingly socially acceptable

ASD boys’ interests intense but not unusual/are social acceptable

Interests of boys with autism often unusual, but increasingly socially acceptable

ASD boys’ interests intense but not unusual/are social acceptable

Areas of special interest differ between boys and girls

ASD girls tend toward more creative/cultural interests
Japanese culture seen more in ASD girls and less in ASD boys
ASD girls interest in mimicking another person can become obsessional

ASD girls’ interests more social
ASD boys’ interests less social

Computer special interests becoming socially acceptable for males
ASD boys’ interests pursue with intensity
ASD girls’ interest in mimicking another person can become obsessional

Girls might not have intense special interests
ASD girls can have intensity without specific interest

ASD girls’ interests pursued with intensity
ASD girls’ interests lacking intensity

Contradictions among participants over the intensity of special interests in boys and girls

ASD girls can have intensity without specific interest
ASD girls might not have intense special interests
Beliefs about gender differences in rigidity are inconsistent among participants.

ASD girls less rigid than ASD boys.

ASD girls more rigid than ASD boys.

There are gender differences in the application of rigidity.

Rigidity linked to cognitive, social and anxiety difficulties.

Quality of rigidity is different in boys and girls with Autism.

ASD boys' rigidity about repetitive behaviors/rituals/other keeping to standards.

ASD girls using rigid black and white thinking style to understand/work out social stuff.

ASD girls easier to redirect/better at following others agendas than ASD boys.

Rigidity can be more subtle in girls, but easier to detect than social difficulties.

Easier to see rigidity rather than social stuff in ASD girls.

ASD girls' rigidity around routines/how things should be done/self following standards.

ASD girls possibly more perfectionistic.

Rigidity in girls with autism focused on routines, and keeping to their own standards.

ASD girls feeling sense of injustice against them.

ASD boys' rigidity about repetitive behaviors/rituals/other keeping to standards.
Boys and girls with Autism tend towards gender stereotypical play. Gender neutral (computer) games popular with ASD boys and ASD girls. ASD girls pretending to be animals, ASD boys taking on sci-fi/computer game roles. Motivation a difficulty in ASD, linked to imagination. Underlying imaginative ability of girls and boys equally impaired. Different opinions amongst participants about fantasy/reality blurring in imaginative play. ASD boys more likely to get fantasy/reality blurring than ASD girls. ASD girls more likely to get fantasy/reality blurring than ASD boys. No gender differences in the likelihood of fantasy/reality blurring between ASD boys and ASD girls. ASD girls appear more imaginative on the surface than ASD boys. ASD boys imaginative play poorer/absent. ASD boys imaginative play requires a premise. Imaginative play of girls with Autism looks superficially better than play of boys with autism. ASD girls can look imaginative but actually copied/repetitive/scribbled/inflexible. No gender differences in social imagination. The underlying imaginative ability of girls and boys equally impaired.
ASD girls are social, at least on
the surface

ASD boys don’t fit in

ASD girls socially better than
ASD boys

ASD boys and girls become
isolated, and struggle to reengage after isolation

ASD girls finding social too hard
and withdrawing

Limited differences on social
ability between ASD boys and
ASD girls

ASD boys and ASD girls both
struggle in social groups

On the surface, girls with
autism appear socially more
interested and able

Girls and boys with autism
becoming isolated

Girls and boys with autism
both struggling with social
interaction
Social interaction in girls and
boys with autism

Friendships of boys with
autism

Nature of friendships different
between ASD boys and ASD
girls

ASD boys and girls seeking out
low demand playmates

Friendships of girls with
Autism

ASD and NT boys’ social
interaction simpler

ASD and NT girls’ social
relationships more complex

ASD and NT boys’ social
behaviour different to ASD and
NT girls’ social behaviour

ASD boys struggle with
empathy, ASD girls appear
better at empathy

ASD girls have better emotional
recognition of others than ASD
boys

Nature of friendships for
girls and boys with autism

Girls with autism tend to be
better at empathy than boys
with autism

Friendships

Universal gender diﬀerences
in friendships

ASD and NT boys less social
interest/ability

ASD and NT girls have greater
social ability/drive/awareness/
copying/communication

ASD boys’ friendships (if any)
tend to be based on games
(real or online) or adult are
maintained

ASD boys might have
mothering female friends

ASD girls’ friendships can be
helpful

ASD girls struggling to keep
and/or maintain friendships, so
often on the periphery or falling
out

ASD girls having one,
sometimes obsessive,
friendship

ASD girls can be more
controlling in social situations


Factors influencing presentation of boys and girls over time.

Older vs younger presentation of ASD boys and girls

Fantasy/reality blurring likely for younger kids with ASD

Younger ASD boys present more clearly as ASD, and may have nurturing female friends.

Older ASD boys can present with low school attendance, withdrawing, might have a niche (e.g. football). If talkative likely to get good grades. Similar to ASD girls in some ways.

Younger ASD girls present as quiet, not asking questions, appear to have some friends, but may still get it wrong and not understand emotions.

Older ASD girls can present with anxiety, low school attendance, reduction in social connections, and might stop trying socially.

Secondary school transition difficult for children with ASD

Greater environmental demands in high school transition

Hard for ASD kids to meet high school demands/transition complexity

There is a social developmental jump that occurs for boys and girls with autism

Social complexity for girls increases in early teenage years

ASD girls can't keep up with increase in social complexity in early teenage years

ASD girls have a different social developmental trajectory

Younger high-functioning ASD girls' kids do on first presentation but meet criteria later when social complexity increases

Older HF kids learn to compensate, but can't keep up with social development

People with ASD not making social developmental jump

Clinicians knowing a person (usually high functioning ASD girl) is going to represent with problems and meet criteria in the future. However, although they will meet criteria, they don't yet, so can't get a diagnosis.

Young people presenting sub-clinically, but experienced clinicians know they will re-present after social-developmental jump

Younger (high functioning/ASD girls) kids ok on first presentation but meet criteria later when social complexity increases

Older HF kids learn to compensate, but can't keep up with social development

People with ASD not making social developmental jump

Clinicians knowing a person (usually high functioning ASD girl) is going to represent with problems and meet criteria in the future. However, although they will meet criteria, they don't yet, so can't get a diagnosis.

Older vs younger presentation of ASD boys and girls

Younger ASD girls present as quiet, not asking questions, appear to have some friends, but may still get it wrong and not understand emotions.

Older ASD girls can present with anxiety, low school attendance, reduction in social connections, and might stop trying socially.

Younger ASD boys present more clearly as ASD, and may have nurturing female friends.

Older ASD boys can present with low school attendance, withdrawing, might have a niche (e.g. football). If talkative likely to get good grades. Similar to ASD girls in some ways.

Younger ASD girls present as quiet, not asking questions, appear to have some friends, but may still get it wrong and not understand emotions.

Older ASD girls can present with anxiety, low school attendance, reduction in social connections, and might stop trying socially.

Greater environmental demands in high school transition

Hard for ASD kids to meet high school demands/transition complexity
Clinicians’ conceptions of autism

The way autism is defined

Triadic and dyadic conceptualisations of ASD

Dimensional view of ASD

Strengths and limitations of the triad

Triadic vs Dyadic models

Diagnostic criteria based on social, communication and RRBIs

Each part of the triad needs to be present at some time in history, and have impact on the person for a diagnosis

Different clinician’s weighting and categorises leads to confusion for families

Triadic viewpoint leads to:

- Social and communication
- Communication and social interaction

Dyadic viewpoint leads to:

- Social
- Communication

ASD defined by lack of developmental gains

Diagnosis made by developmental gains

Rigidity not part of Autism?

Communication and social interaction show linked and influence each other but separately

ASD boys obvious

ASD boys and girls present differently

ASD girls biologically protected

ASD girls are somewhat protected against ASD, meaning they present as higher functioning/more able

Girls with autism (without a learning disability) tend to be high functioning and subtle

ASD girls more subtle

ASD girls under the radar

ASD girls high functioning

Girls with ASD present with less RRBIs

ASD boys and ASD girls different but lots of variation in ASD presentation within and between genders - differences might be subtle or minimal
Effects of culture on Autism

People have different expectations for ASD boys and ASD girls.

- People don't expect or accept ASD in girls.
- ASD in boys culturally acceptable.
- There is a lack of awareness of girls with Autism.
- There is a lack of awareness of what girls with autism look like, stopping them being assessed.
- Mental Health professionals need to be aware and think about ASD in the girls they see.
- Need to increase awareness of ASD in girls and how to look for it.
- People need to realise ASD is different in girls.
- People don't think ASD for girls having problems but have yet to identify the cause of the problems.
- Schools (and parents) not picking up ASD girls for assessment, better at ASD boys.
- Professionals find it hard to think about ASD in girls, especially if complex or just about managing.

Culture provides ASD girls with opportunities and risks.

- ASD girls more exposed to experiences of practice imagination.
- ASD girls more susceptible to culture.
- There is a cultural stereotype that boys are boisterous/nerdy, girls are empathetic/mean.
- Huge cultural pressures for girls.
- We socialise boys and girls differently.
- Gender differences in tolerance of difference.

People with Autism are affected by the culture they live in.

- Culture impacts PPRs.
- ASD girls more exposed to experiences of practice imagination.
- ASD girls more susceptible to culture.
- There is a cultural stereotype that boys are boisterous/nerdy, girls are empathetic/mean.
- Huge cultural pressures for girls.
- We socialise boys and girls differently.
- Gender differences in tolerance of difference.

Culture has specific impacts on girls with autism.

- Differential effect of culture on gender regardless of presence/absence of autism.
- Culture impacts RRBIs.
- ASD girls more exposed to experiences to practice imagination.
- ASD girls more susceptible to culture.
- There is a cultural stereotype that boys are boisterous/nerdy, girls are empathetic/mean.
- Huge cultural pressures for girls.
- We socialise boys and girls differently.
- Gender differences in tolerance of difference.

There is a lack of awareness of girls with Autism.

- People don't expect or accept ASD in girls.
- ASD in boys culturally acceptable.
- There is a lack of awareness of what girls with autism look like, stopping them being assessed.
- Mental Health professionals need to be aware and think about ASD in the girls they see.
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- Schools (and parents) not picking up ASD girls for assessment, better at ASD boys.
- Professionals find it hard to think about ASD in girls, especially if complex or just about managing.

Society more accepting/more quirky.

- People with Autism are affected by the culture they live in.
- Culture impacts PPRs.
- ASD girls more exposed to experiences of practice imagination.
- ASD girls more susceptible to culture.
- There is a cultural stereotype that boys are boisterous/nerdy, girls are empathetic/mean.
- Huge cultural pressures for girls.
- We socialise boys and girls differently.
- Gender differences in tolerance of difference.

Differential effect of culture on gender regardless of presence/absence of autism.

- There is a lack of awareness of what girls with autism look like, stopping them being assessed.
- Mental Health professionals need to be aware and think about ASD in the girls they see.
- Need to increase awareness of ASD in girls and how to look for it.
- People need to realise ASD is different in girls.
- People don't think ASD for girls having problems but have yet to identify the cause of the problems.
- Schools (and parents) not picking up ASD girls for assessment, better at ASD boys.
- Professionals find it hard to think about ASD in girls, especially if complex or just about managing.

Gender differences in tolerance of difference.

- People have different expectations for ASD boys and ASD girls.
- People struggle to understand and remember ASD in girls.
- Mental Health professionals need to be aware and think about ASD in the girls they see.
- Need to increase awareness of ASD in girls and how to look for it.
- People need to realise ASD is different in girls.
- People don't think ASD for girls having problems but have yet to identify the cause of the problems.
- Schools (and parents) not picking up ASD girls for assessment, better at ASD boys.
- Professionals find it hard to think about ASD in girls, especially if complex or just about managing.

Mental Health professionals need to be aware and think about ASD in the girls they see.

- Need to increase awareness of ASD in girls and how to look for it.
- People need to realise ASD is different in girls.
- People don't think ASD for girls having problems but have yet to identify the cause of the problems.
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There is a lack of awareness of what girls with autism look like, stopping them being assessed.

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- Schools (and parents) not picking up ASD girls for assessment, better at ASD boys.
- Professionals find it hard to think about ASD in girls, especially if complex or just about managing.
Gender differences in diagnostic routes

Boys are picked up for autism assessment young, girls are picked up when teenagers.

ASD boys picked up young due to hyperactivity, ADHD, or externalising behaviour.

ASD girls picked up due to mental health issues, often anxiety or depression.

ASD girls in particular presenting to mental health services with anxiety, but underlying ASD not picked up.

Professionals only see (or want to see) the mental health problems of girls with autism, not the underlying undiagnosed autism.

Confirmation bias – once labelled as anxiety cannot be anything else.

Professionals prefer to refer girls for Mental Health intervention rather than ASD assessment.

ASD girls vulnerable to diagnostic overshadowing, usually by anxiety or other mental health conditions.

Eating disorders can look like ASD, so ASD girls can be mis-diagnosed.

Under diagnosis of ASD girls.

There are several secondary or comorbid diagnoses common in boys and girls with autism.

Under diagnosis of ASD girls.

ASD girls picked up at transition from primary to high school, due to differences in demands/support.

ASD boys get ADHD or behaviour labels, girls with autism get mental health labels.

Gender differences in diagnostic routes

Boys with autism-picked up young because of behavioural issues.

ASD girls and ASD boys have different routes to diagnosis.

ASD girls picked up due to Mental Health.

ASD boys present to Mental Health services with anxiety but underlying ASD not picked up.

ASD girls picking up secondary/comorbid anxiety but autism is not picked up.

ASD girls picked up for diagnosis later than ASD boys.

ASD girls, particularly pre-teen, often not picked up for assessment.

ASD girls coming for diagnosis after often manage years, ASD boys coming for diagnosis in childhood.

Girls with autism-picked up young because of anxiety problems, but often missed.

ASD boys picked up young due to hyperactivity, ADHD, or externalising behaviour.

ASD girls picked up for autism assessment later due to mental health issues.

ASD overlaps/overdiagnoses with conditions: ADHD, Depression.

Girls with autism are under or not diagnosed.

No gender differences in people with ASD getting PD labels.

ASD boys get different labels to ASD girls (ADHD vs mental health).

ASD girls externally acting up, behaviour leads to assessment for ASD and/or other conditions.

ASD girls and ASD boys have different routes to diagnosis.

Professionals only see (or want to see) the mental health problems of girls with autism, not the underlying undiagnosed autism.

Confirmation bias – once labelled as anxiety cannot be anything else.

Professionals prefer to refer girls for Mental Health intervention rather than ASD assessment.

ASD girls vulnerable to diagnostic overshadowing, usually by anxiety or other mental health conditions.

Eating disorders can look like ASD, so ASD girls can be mis-diagnosed.

ASD kids picked up at transition from primary to high school, due to differences in demands/support.

Boys with autism get ADHD or behaviour labels, girls with autism get mental health labels.

No gender differences in people with ASD getting PD labels.

ASD boys get different diagnoses to ASD girls (ADHD vs mental health).

ASD girls present to Mental Health services with anxiety but underlying ASD not picked up.

ASD girls picking up secondary/comorbid anxiety but autism is not picked up.

ASD boys picked up young due to hyperactivity, ADHD, or externalising behaviour.

ASD girls picked up later (often teenage years). ASD boys coming for diagnosis in childhood.

Girls with autism-picked up young because of anxiety problems, but often missed.

ASD girls picked up due to Mental Health.

ASD boys presented to Mental Health services with anxiety but underlying ASD not picked up.

ASD girls picking up secondary/comorbid anxiety but autism is not picked up.

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Girls with autism-picked up young because of anxiety problems, but often missed.

ASD girls picked up due to Mental Health.

ASD boys presented to Mental Health services with anxiety but underlying ASD not picked up.

ASD girls picking up secondary/comorbid anxiety but autism is not picked up.
Orientating model to superordinate theme "making a diagnostic decision" on next page, with subsections of the theme on the following pages.
Making a diagnostic decision

Importance of formulating a diagnosis

The use of diagnostic criteria

Gathering data is part of an assessment for Autism, but especially important for girls, or complex cases

How to conduct an assessment for autism

Experience and judgement needed, particularly for ASD girls

The use of standardised measures in autism assessments

Gender Bias exists, and will interfere with any assessment process

Considerations when giving a diagnosis
Importance of formulating a diagnosis

Need to question the evidence contributing to an assessment

Need to be particularly questioning of evidence when assessing ASD girls

Need to question results of structured assessments, including ADOS

Need to question all evidence informing assessment and investigate discrepancies

Informants and indirect info not ideal, and can be wrong/biased

Areas to consider in a formulation

Diagnostic formulation needs to consider environment, developmental opportunities and cultural influences

Diagnostic formulation needs to consider genetics, neurodevelopment and cognitive development

Diagnostic formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans diagnostic categories (internalising/externalising)

A diagnostic formulation is needs focused and exploratory, not confirmatory

Formulating a diagnosis important, especially for ASD girls/complex cases

Formulation not a tick box “can I explain it this way” exercise

Important to consider other diagnoses/is diagnosis needed

Lots of things (attachment, LD, etc) can look like ASD

Diagnostic formulation should be needs focused

A diagnostic formulation is needs focused and exploratory, not confirmatory

Need to question the evidence contributing to an assessment

Important to consider other diagnoses/is diagnosis needed

Lots of things (attachment, LD, etc) can look like ASD

Diagnostic formulation should be needs focused

Formulation not a tick box “can I explain it this way” exercise

Diagnostic formulation needs to consider environment, developmental opportunities and cultural influences

Diagnostic formulation needs to consider genetics, neurodevelopment and cognitive development

Diagnostic formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans diagnostic categories (internalising/externalising)

Diagnostic formulation needs to consider environment, developmental opportunities and cultural influences

Diagnostic formulation needs to consider genetics, neurodevelopment and cognitive development

Diagnostic formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans diagnostic categories (internalising/externalising)
The use of diagnostic criteria DSM-4 vs DSM-5 vs ICD 10
DSM-4/ICD-10 has a narrow, classical, rigid view of ASD
DSM-5 more flexible, takes a dimensional view and looks more at longevity and impact
DSM-5 better and preferred
Diagnostic criteria as a tool for clinical thinking
Clinical judgement needed to apply/interpret/overrule diagnostic criteria
Diagnostic criteria useful as a framework/guide to thinking
Diagnostic criteria are fuzzy, requiring interpretation
Diagnostic criteria "loose" and subject to interpretation
No clear line between NT and ASD
Criteria are a pick and mix; many criteria sufficient, but not all necessary/equal
Diagnostic criteria not as good as formulation (longevity, functioning, support, etc)
Diagnostic criteria not to be used as a "tick box" exercise
Experienced clinicians don't use diagnostic criteria as a tick box exercise
Risk of mis/under-diagnosis if using criteria as a tick box exercise
Problems with diagnostic criteria
Diagnostic criteria struggling to capture non-transitional presentations
Social communication section not capturing some girls or high functioning girls
Diagnostic criteria interfering/blaming against girl's with autism
High functioning not scoring as high as social communication or diagnostic criteria
ASD gets labeled at 6, high functioning gets labeled higher for ASD girls, lower for ASD boys in most criteria
Diagnostic criteria biased against girls or high functioning girls
Diagnostic criteria can be improved
Diagnostic criteria that are not capturing girls or same high functioning boys
Diagnostic criteria that are not capturing girls or some high functioning presentations
Diagnostic criteria not capturing non-transitional presentations
Diagnostic criteria can be improved
Normalisation of presentation/normalisation of diagnosis
DSM-5 more flexible, takes a dimensional view of autistic and atypical
DSM-4 has rigid categories
DSM-5 gives a spectrum
DSM-5 allows for gradations
Diagnostic criteria can be used as a tool for clinical thinking
Diagnostic criteria not as good as formulation (longevity, functioning, support, etc)
Diagnostic criteria not to be used as a "tick box" exercise
Experienced clinicians don't use diagnostic criteria as a tick box exercise
Risk of mis/under-diagnosis if using criteria as a tick box exercise
Problems with diagnostic criteria
Diagnostic criteria missing things, such as anxiety, thinking style, executive functioning, etc.
You can hide ASD if you have average to high IQ
There shouldn't be variability in whether someone gets a diagnosis due to team or the child's development
PDA sometimes (but not always) meeting ASD diagnostic criteria
Diagnostic criteria can be used as a tool for clinical thinking
Diagnostic criteria can be improved
Diagnostic criteria for autism spectrum
Diagnostic criteria not to be used as a "tick box" exercise
Gathering data is part of an assessment for Autism, but especially important for girls, or complex cases.

360 degree view important, particularly when assessing girls.

History, observation, and reports from multiple sources needed to get 360-degree view required for Assessment (may not need ADOS).

Parental report important but might need to probe (but don’t dismiss!).

School/teacher reports of ASD girls require more probing/questioning to pin down ASD behaviours.

ASD girls more likely to present fine at school, but ‘decompress’ at home.

Having enough time is important in providing good, high quality diagnostic assessment.

Having enough time to get to know the person important in the assessment process.

Multi-disciplinary team important in assessment, especially for ASD girls.

History is a very important part of assessment, particularly for girls or complex cases.

History is a very important part of assessment, particularly for girls or complex cases.

360 degree view important, particularly when assessing girls.

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Having enough time to get to know the person important in the assessment process.

Multi-disciplinary team important in assessment, especially for ASD girls.
How to conduct an assessment for autism

Key areas to consider when assessing for Autism

Emotional response a key diagnostic indicator for ASD boys and ASD girls

Social interaction and communication key when assessing for Autism

Friendships (starting/maintenance/understanding) important to evaluate when assessing for ASD

Language difficulties in literality/misinterpreting/echolalia difficult to hide

Sense of reciprocity, of thinking about me correctly in this situation key ASD indicator

RRBs may not be present in assessment, only by history or report

Considerations when assessing girls and high functioning boys

Autism fundamentally the same in boys and girls, but girls and high functioning boys difficult to identify

Girls and high functioning boys masking their difficulties in assessment

Have to work harder to unravel ASD girls' masking; They would be the same as boys if they didn't mask.

ASD girls (and some high functioning ASD boys) likely to give surface/learned answers with only one or two red flags. Need to dig deep and check for real understanding

ASD girls (and some high functioning ASD boys) don't present in a typical ASD way. They mask, and can know what to do and say to pass assessment

Inconsistencies over comparison group. Clinicians comparing client to ASD peers or to NT peers

Boys and older girls more likely to refuse to answer/engage

ASD boys and older ASD girls most likely to refuse to engage in assessment

ASD boys likely to refuse to answer if don't know, ASD girls likely to try to answer

The 'core' of Autism is the same in girls and boys, but may present differently in assessment

Assessment process, and what you are looking for is the same for ASD boys and ASD girls, but presentation and thinking around assessment may differ

ASD boys easier to diagnose, ASD girls harder to diagnose

High functioning girls and boys with autism require more presses, depending on ability and gender

RRBs difficult to pick up on in assessment

Higher functioning kids can mask RRBIs

Have to dig to tempt ASD girls to talk about special interests

Social imagination tasks can be imitated through intellectualisation, rather than understanding

ASD girls are able to intellectualise though social imagination tasks on the ADOS, so need to push them (change the story, add complexity)

ASD girls (and high functioning ASD boys) can intellectualise through play assessment. Need to consider if this is imaginative or rehearsed? Are they engaging the examiner correctly?

Social communication often appears good in girls/high functioning boys through learning.

Have to unpick HF ASD girls (and HF boys) social communication: is it learned/mimicked? Use self as a social tool to find out

ASD girls use more and better gesture on the ADOS than ASD boys, but might appear over-dramatic/over-learned

High functioning ASD girls (and high functioning boys) often have good social communication

Language (echolalia/unusual) key indicator of ASD in girls

ASD girls likely to chat in assessment. Easy to assume they are fine. Need to really evaluate/push/challenge to see if true reciprocity

Emotional responses and understanding are a key part of ASD Assessment

ASD boys saying "don't know" or rehearsed answer to emotional questioning

ASD girls may be able to label emotions in a book but might struggle to talk about them properly. Need to tease this out

ASD girls more likely to become "unstuck" on emotion and friendships, so need to probe these more

Have to probe/test emotional understanding in ASD girls (less so in ASD boys)

ASD girls can do better/pass emotional recognition and understanding tasks
Considerations when giving a diagnosis

Persons perspective on diagnosis and if they want a diagnosis important

Diagnosis must be at the right time for the person and their family

The value of a diagnosis

"Would a diagnosis be helpful" an important consideration

Diagnosis not as useful as the support it accesses

Diagnosis can reduce the persons and their family's anxiety

Diagnosis can help the person understand themselves

Limited gender differences in post diagnostic support

Use of terminology can be confusing or disliked by some families

ASD girls more likely to worry about sharing diagnosis

No gender differences in post diagnostic support offered, uptake (although internalising/externalising will lead to differences in mental health support)

Families prefer Aspergers or PDA diagnosis, and dislike an autism label (as in DSM-5)

Clinicians having to explain different terminology (PDA, DSM-5) that families find confusing

ASD girls more likely to worry about sharing diagnosis

No gender differences in post diagnostic support offered, uptake (although internalising/externalising will lead to differences in mental health support)

Families prefer Aspergers or PDA diagnosis, and dislike an autism label (as in DSM-5)

Clinicians having to explain different terminology (PDA, DSM-5) that families find confusing
Gender Bias exists, and will interfere with any assessment process.

Clinicians' gender affects assessment.

- Male assessors have lower standards (for social communication and interaction) than female assessors.
- Male assessors find it harder to talk about ASD girls' interests and give less social openings.
- Males and females with ASD will react differently to male and female assessors.

Cannot avoid examiner gender bias. What is important is being aware of it and getting multiple perspectives.

Informants have gender biases and preconceptions that will influence their interpretation and reporting of gender biases.

Observers will interpret behaviour in a way that is influenced by their existing gender biases.
The use of standardised measures in autism assessments

The ADOS (and other measures) struggle to capture non-traditional presentations

Need to reset neurotypical benchmark on ADOS

Gender differences in ADOS (and other measures)

Standardised measures important part of Assessment, but take with pinch of salt for ASD girls

Disagreement over whether ADOS administered/scored differently for ASD boys/ASD girls

ADOS good, but limited on ability to measure insight/social relationship skill

ADOS won’t pick up on emotion regulation difficulties, ADI will

The ADOS can detect differences in language and social communication for most children

ADOS go old, but limited on ability to measure insight/social relationship skill

ADOS won’t pick up on emotion regulation difficulties, ADI will

High Functioning ASD girls (and boys) can pass ADOS through subtle learning, although might still have slight unusual presentation

Error of measurement in ADOS (ADOS measures)

Gender differences in ADOS (and other measures)

High functioning ASD girls can score up ok on ADOS

ADOS a tool, not a diagnosis

ADOS and other measures not sensitive to ASD girls

Pre-teen ASD girls not being picked up on ADOS, re coming track, as teenagers; and getting diagnosis

ADOS one piece of the puzzle, cannot base diagnosis on ADOS alone

ADOS scoring subject to interpretation, needs to interpret correctly (for girls)

Careful interpretation of standardised measures (ADOS) important

ADOS a tool, not a diagnosis

ADOS and other measures not sensitive to ASD girls

Pre-teen ASD girls not being picked up on ADOS, re coming track, as teenagers; and getting diagnosis

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Pre-teen ASD girls not being picked up on ADOS, re coming track, as teenagers; and getting diagnosis

ADOS one piece of the puzzle, cannot base diagnosis on ADOS alone

ADOS scoring subject to interpretation, needs to interpret correctly (for girls)
Experience and judgement needed, particularly for ASD girls. Using a gut feeling as a useful tool, but use with caution.

Gut feeling about socio-emotional connectedness. Gut feeling delayed/subtle in ASD girls, but important. Common and easy in ASD boys.

Clinical judgement needed particularly for ASD girls. Experience needed when assessing for ASD, particularly for girls.

People coming to Tier 3 getting diagnosis due to different criteria and being able to look at softer symptoms. Clinical experience needed to unpick coping strategies and notice subtler presentations.

Experience helps you know what you are looking for. Experience allows clinicians to get to know how ASD girls present.

Clinical judgement can/should overrule measure or diagnostic criteria. Clinical experience allows clinicians to question/or阀measures.

Different professionals can disagree over ASD diagnosis; difference in perspectives/expertise?

Experience helps clinicians to know what they are looking for. Experience allows clinicians to get to know how ASD girls present.

Overruling diagnostic measures/criteria.

Clinical judgement needed, particularly for ASD girls. Experience needed when assessing for ASD, particularly for girls.

Person can get diagnosis even when evidence poor/contradictory.


Clinical judgement can/should overrule measure or diagnostic criteria. Clinical experience allows clinicians to question/or valve measures.
Appendix 2K: Codes removed from stage 6

- Social communication/interaction problem key concern to people with ASD and their families
- People with autism acting younger or older than their chronological age
- Potential for intervention in autism in near future (social communication)
- Circularity compromising existing evidence base
- Risk of small number of ASD girls and confirmation bias in my own research
Appendix 2L: Full interpretive model from stage 7

Due to the complexity of this model, it is not possible to adequately reproduce it in paper format. A PDF of this model can be found at www.tinyurl.com/JMThesis, and opened using the password “Wing1979”

Note that themes are indicated by **bold**. Codes with less than 6 descriptors and less than three contributors are written in **red**.

A partial reproduction of the model is on the following 23 pages.

This model consists of five superordinate themes. The three smallest superordinate themes are presented in their entirety on the first three pages. After this, the remaining two large themes are presented. As with appendix 2J, both superordinate themes are too big to be presented by themselves. Instead, an orientating model for each is presented, followed by smaller models, each originating from a node on the orientating model. These smaller models can be identified by their single colour, as opposed to the multicolour models which show a superordinate theme.
Autism is defined and modified by our culture. Because autism is defined as being for boys, girls find it harder to be picked up for assessment and to get support. People have different expectations of girls and boys with autism, leading to differences in support. Autism is culturally acceptable for boys, but not for girls. People don't expect or dismiss ASD in girls. ASD in boys culturally acceptable. Different expectations for ASD boys and ASD girls. People struggle to understand and remember ASD in girls. People do not know how autism is different in girls, meaning they are not picked up nor considered for assessment. Schools, parents and professionals lack awareness of how autism is different in girls and do not look out for it. Professionals are not used to assessing girls for autism, so prefer to consider other explanations. Mental health professionals need to be aware and think about ASD in girls they see. Need to increase awareness of ASD in girls and how to look for it. People need to realize ASD is different in girls. People don't think ASD for girls having problems but have yet to identify the cause of the problems. Schools and parents not picking up ASD girls for assessment, better at ASD boys. Professionals find it hard to think about ASD in girls as used to how boys present, so look for other explanations. Professionals anxious about diagnosing girls with ASD, especially if complex or just about managing. People need to realize ASD is different in girls. People don't think ASD for girls having problems but have yet to identify the cause of the problems. Schools and parents not picking up ASD girls for assessment, better at ASD boys. Professionals find it hard to think about ASD in girls as used to how boys present, so look for other explanations. Professionals anxious about diagnosing girls with ASD, especially if complex or just about managing. There is a cultural stereotype that boys are boisterous/nerdy, girls are empathetic/mean. Huge cultural pressures to girls. We socialise boys and girls differently. Gender differences in tolerance of difference. Our understanding of child development and what is normal has changed over time in tandem with our cultural changes. Our view of autism, its name and its features have changed over time and will continue to change. ASD girls more exposed to experiences to practice imagination. Culture provides ASD girls with opportunities and risks. Culture impacts RRBs. ASD girls more susceptible to culture. Regardless of diagnosis, boys and girls are affected by the culture they live in. Cultural expectations affect girls and boys and their presentations of autism. People do not know how autism is different in girls, meaning they are not picked up nor considered for assessment. Professionals are not used to assessing girls for autism, so prefer to consider other explanations. Mental health professionals need to be aware and think about ASD in girls they see. 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ASD girls more exposed to experiences to practice imagination. Culture provides ASD girls with opportunities and risks. Culture impacts RRBs. ASD girls more susceptible to culture. Regardless of diagnosis, boys and girls are affected by the culture they live in. Cultural expectations affect girls and boys and their presentations of autism. People do not know how autism is different in girls, meaning they are not picked up nor considered for assessment. Professionals are not used to assessing girls for autism, so prefer to consider other explanations. Mental health professionals need to be aware and think about ASD in girls they see. Need to increase awareness of ASD in girls and how to look for it. People need to realize ASD is different in girls. People don't think ASD for girls having problems but have yet to identify the cause of the problems. Schools and parents not picking up ASD girls for assessment, better at ASD boys. Professionals find it hard to think about ASD in girls as used to how boys present, so look for other explanations. Professionals anxious about diagnosing girls with ASD, especially if complex or just about managing.
Girls with autism are accurately diagnosed, but not getting referred for assessment until later, often after being in mental health services. Boys are picked up young due to their behaviour. Girls are picked up later via mental health services, but autism often goes unrecognised for some time. Girls picked up for diagnosis later than ASD boys. ASD girls, particularly pre-teen hard to pick up for assessment. ASD girls coming for diagnosis later (often teenage years), ASD boys coming for diagnosis in childhood. ASD boys picked up young due to their behaviour, so get referred for ASD assessment. ASD boys externalising behaviour leads to assessment for ASD and/or other conditions.

ASD girls and ASD boys have different routes to diagnosis. Boys are picked up young due to their behaviour. Girls are picked up later via mental health services, but autism often goes unrecognised for some time. Girls are presenting to mental health services, but the underlying autism is not identified. ASD girls getting mis-diagnosed with anxiety/mental health problems. ASD girls coming for diagnosis later (often teenage years), ASD boys coming for diagnosis in childhood. ASD boys externalising behaviour leads to assessment for ASD and/or other conditions. ASD girls picked up for diagnosis later than ASD boys.

Autism has co-morbidities and conceptual overlap with other disorders. Girls with autism are accurately diagnosed, but not getting referred for assessment until later, often after being in mental health services. Girls are now accurately diagnosed, but still under diagnosed. Under diagnosis of ASD girls. Accurate at picking up ASD girls in assessment, but still under diagnosis of girls, and girls more likely to be mis-diagnosed. Hard to disentangle ASD and Anxiety. ASD overlaps/comorbidities with epilepsy, ADHD, Dyspraxia. Professional prefer to refer girls for Mental Health intervention rather than ASD assessment. Confirmation bias – once labelled as anxiety cannot be anything else.

ASD boys get different labels to ASD girls (ADHD vs mental health). No gender differences in people with ASD getting BD labels. ASD boys alternative diagnoses include ADHD, conduct/behaviour problems (sometimes anxiety or query psychosis). ASD boys externalising behaviour leads to assessment for ASD and/or other conditions. ASD boys picked up due to Mental Heath. Eating disorders can look like ASD, so ASD girls can be mis-diagnosed. ASD girls in particular presenting to mental health services with anxiety but underlying ASD not picked up. ASD girls vulnerable to diagnostic overshadowing, usually by anxiety (other mental health conditions). ASD girls picked up for diagnosis later than ASD boys. ASD girls coming for diagnosis later (often teenage years), ASD boys coming for diagnosis in childhood. ASD boys externalising behaviour leads to assessment for ASD and/or other conditions.
While autism is defined by the triad, clinicians conceptualise autism more broadly, but place social interaction and communication at its core.

Autism is defined by the triad of impairments. This is a useful tool, but does not capture everything about autism.

The triad forms the basis of diagnosis, but does not capture everything about autism.

Different clinicians using triad and/or dyad leads to confusion for families.

While the dyad is a step forward in criteria, the triad is more useful.

Triad has limitations, helps to identify strengths and weaknesses.

Triad of impairments not capturing everything about ASD.

Diagnostic criteria based on social, communication and RRBIs.

Each part of the triad needs to be present at some time in history, and have impact on the person for a diagnosis.

Triad is social, communication and RRBIs.

ASD defined behaviorally by diagnostic criteria.

While the dyad is a step forward in criteria, the triad is more useful.

Diagnosis is focused on identifying strengths and weaknesses.

Triad of impairments not capturing everything about ASD.

Diagnostic criteria based on social, communication and RRBIs.

Each part of the triad needs to be present at some time in history, and have impact on the person for a diagnosis.

Triad is social, communication and RRBIs.

ASD defined behaviorally by diagnostic criteria.

People with autism present very differently, but gender differences can be seen in those with high functioning autism.

Classic presentations picked up early (male and female).

Hypervigilance within, not just behavior, genders through multiplicity.

Gender differences at the high functioning end of the spectrum. No differences in classical presentations of Autism.

Classic ASD presentation allows for high functioning ASD presentation.

ASD presentation combination of genes and environment.

Autism is one disorder that can be caused by multiple factors.

Autism is not a “ghost in the machine.”

People with autism have difficulties with sensory sensitivities, social interaction, and social thinking.

Sensory issues underrepresented and impactful. Key part of Autism.

People with Autism see and react to the world differently.

ASD thinking style important in ASD.

Social communication part of ASD.

People with ASD struggle with expressive receptive verbal non-verbal communication.

Diagnostic thinking_DIFF in ASD.

Expressive language better than receptive language for ASD girls and boys.

Lack of awareness of others’ perspectives a key indicator of ASD.

Imaginary play thought outcapital.

While autism is defined by the triad, clinicians conceptualise autism more broadly, but place social interaction and communication at its core.

RRBIs core feature of ASD. Rightly not part of Autism?

Social interaction and communication is the essential “core” of Autism.

RRBIs core feature of ASD. Rightly not part of Autism?

Social interaction and communication is the essential “core” of Autism.

AAAS girls biologically protected.

ASD girls are somewhat protected against ASD, meaning they present as higher functioning/more able.

ASD girls with ASD present differently.

ASD boys and ASD girls present differently.

ASD boys and ASD girls present differently.

Girls have some protection against autism.

ASD boys are under the radar.

ASD girls high functioning.

Girls have some protection against autism, so are more subtle in presentation.

ASD boys and ASD girls present differently.

Girls have some protection against autism.

ASD boys and ASD girls present differently.

ASD girls present with less RRBIs.

ASD girls more subtle.

ASD girls have some protection against autism.

Girls have some protection against autism, so are more subtle in presentation.

ASD boys and ASD girls present differently.

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Gender differences at the high functioning end of the spectrum. No differences in classical presentations of Autism.

Classic ASD presentation allows for high functioning ASD presentation.

Asd presentation combination of genes and environment.

Autism is one disorder that can be caused by multiple factors.

Autism is a neurodevelopmental disorder.

Autism has many etiologies that create same flavour of presentation.

Girls with ASD present with less RRBIs.

ASD boys and ASD girls present differently.

Girls have some protection against autism.

ASD boys and ASD girls present differently.

ASD boys and ASD girls present differently.

ASD boys and ASD girls present differently.

ASD boys and ASD girls present differently.

ASD boys and ASD girls present differently.

Gender differences at the high functioning end of the spectrum. No differences in classical presentations of Autism.

Classic ASD presentation allows for high functioning ASD presentation.

ASD presentation combination of genes and environment.

Autism is one disorder that can be caused by multiple factors.

Autism is a neurodevelopmental disorder.

Autism has many etiologies that create same flavour of presentation.
Orientating model to superordinate theme “Girls and boys with autism are exactly the same but have completely different presentations” on next page, with subsections of the theme on the following pages
Girls and boys with autism are exactly the same but have completely different presentations.

Girls and boys can be equally rigid, but apply that rigidity differently.

Girls and boys have the same imaginative ability and their play is equally affected by culture. Girls' imaginative play looks better.

While boys and girls have the same intensity in their special interests, girls' are often typical of other girls' interests, so harder to spot.

Underlying social ability in girls and boys likely to be the same, but girls appear more social, and more actively trying to maintain friendships.

Girls and boys often have mental health problems, but cope differently.

Younger girls and boys may present differently, but as the complexity of social relationships increases their presentations become similar.

Girls are more likely to be aware they are different and want social relationships, so copy others and mask their difficulties.

Girls and boys with autism have the same communicative ability, but girls' social communication often looks superficially better.
Girls and boys often have mental health problems, but cope differently. Being social and flexible gets you support. Social warmth gets you support. Social warmth linked with sociability/flexibility. Female professionals delivering social/communication based intervention; is this meeting the needs of predominantly male clients? ASD girls and ASD boys talk differently in therapy. Have to work hard to get ASD boys to talk about thoughts. ASD girls appear to engage better in therapy. ASD girls in therapy have complex/unusual/learned responses. Therapy modifications for ASD. ASD girls internalising NT girls more reflective than NT boys. NT girls internalising, NT boys externalising. ASD boys externalising driven by anxiety/emotional regulation. ASD girls avoid demands. ASD boys confront/refuse demands. ASD girls passive in friendships. ASD girls “in their own heads”. ASD girls fantasy worlds could be escapist. NT and ASD girls more compliant/perfect/obedient. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. Cost of coping for ASD girls (mental health). ASD girls trying to cope, at a cost.

People with autism are likely to develop mental health problems. School and bullying at school cause mental health problems. Social awareness means you know you don’t fit in. Boys and girls with ASD are anxious. Rigid/cause of anxiety. Nature and nurture, combined with internalising/externalising, lead to passivity/avoidance in the face of anxiety. ASD girls internalising. NT girls more reflective than NT boys. NT girls internalising, NT boys externalising. ASD boys have more acting out/externalising behaviours. ASD boys externalising driven by anxiety/emotional regulation. ASD girls avoid demands. ASD boys confront/refuse demands. ASD girls passive in friendships. ASD girls “in their own heads”. ASD girls fantasy worlds could be escapist. NT and ASD girls more compliant/perfect/obedient. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. Cost of coping for ASD girls (mental health). ASD girls trying to cope, at a cost.

People with autism likely to have mental health problems. Girls and boys often have mental health problems, but cope differently. Girls more likely to engage successfully in therapy. Female professionals delivering social/communication based intervention; is this meeting the needs of predominantly male clients? ASD girls and ASD boys talk differently in therapy. Have to work hard to get ASD boys to talk about thoughts. ASD girls appear to engage better in therapy. ASD girls in therapy have complex/unusual/learned responses. Therapy modifications for ASD. ASD girls internalising NT girls more reflective than NT boys. NT girls internalising, NT boys externalising. ASD boys externalising driven by anxiety/emotional regulation. ASD girls avoid demands. ASD boys confront/refuse demands. ASD girls passive in friendships. ASD girls “in their own heads”. ASD girls fantasy worlds could be escapist. NT and ASD girls more compliant/perfect/obedient. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. ASD girls coping with social stuff leads to anxiety. Cost of coping for ASD girls (mental health). ASD girls trying to cope, at a cost.
Younger girls and boys may present differently, but as the complexity of social relationships increases, their presentations become similar.

Boys and girls initially present differently, but their presentations become similar over time.

Fantasy/reality blurring likely for younger kids with ASD.

Younger ASD boys present more clearly as ASD, and may have nurturing female friends.

Older ASD boys can present with low school attendance, withdrawing, and might have a niche (e.g., football). They might get good grades.

Similar to ASD girls in some ways.

Younger ASD girls present as quiet, not asking questions, and may still get it wrong, not understanding emotions.

Older ASD girls can present with anxiety, low school attendance, reduction in social connections, and might stop trying socially.

There is a social-developmental jump which girls are more likely to struggle with, making their social difficulties more obvious.

Social complexity for girls increases in early teenage years.

ASD girls can’t keep up with increased social complexity in early teenage years.

ASD girls have a different social developmental trajectory.

Younger children can present as not meeting diagnostic criteria, but clinicians know they will meet criteria later in life.

Younger (high functioning/ASD) girls are ok on first presentation but meet criteria later when social complexity increases.

Older HF kids learn to compensate, but can’t keep up (with social development).

People with ASD not making social developmental jump.

Clinicians knowing a person (usually high functioning ASD girl) is going to represent with problems and meet criteria in the future. However, although they will meet criteria, they don’t yet, so can’t get a diagnosis.

Children with autism struggle with the transition from primary to secondary school.

Greater environmental demands in high school transition.

Hard for ASD kids to meet high school demands/transition complexity.

ASD kids picked up at transition from primary to high school due to differences in demands/support.

ASD girls picked up at transition from primary to secondary school, due to differences in demands/support.
Girls are more likely to be aware they are different and want social relationships, so copy others and mask their difficulties. Girls likely to have better social awareness than boys, but still vulnerable. The limited social awareness of girls with autism makes them vulnerable. Clinicians' have particular worries about the vulnerability of ASD girls. Extent of ASD girls social awareness. Girls with autism likely have greater social awareness, but still vulnerable. ASD boys' social awareness more variable. Gender differences in social responses/ability make gender differences in social awareness hard to judge. ASD girls have greater social awareness than ASD boys. Social awareness leads to awareness of difference, leads to social motivation, leads to wanting to fit in, leads to mimicking/copying, if able. Insight helps you ask for help. Girls with autism want have a social identity. ASD boys less fussed about consequences of not engaging. No gender differences in social drive in ASD. ASD girls have social motivation but difficulty acting on it successfully. ASD boys have social motivation, but are better at it. ASD girls have higher social motivation than boys. ASD girls have social differences that only sometimes show. Some ASD girls can try to copy/mimic how to interact and hide their difficulties, but more ASD girls do it, and are better at it. ASD girls have higher social motivation than boys. ASD girls have more social awareness than boys. Girls are more likely to be aware they are different and want social relationships, so copy others and mask their difficulties. Girls likely to have better social awareness than boys, but still vulnerable. Social awareness leads to awareness of difference, leads to social motivation, leads to wanting to fit in, leads to mimicking/copying, if able. Insight helps you ask for help. Girls with autism want have a social identity. ASD girls have higher social motivation than NT girls. ASD girls social drive lower than NT girls. ASD girls' desire to fit in, be part of groups, have friendships and relationships is fueling social motivation. Girls with autism want have a social identity. ASD girls fear not fitting in, saying or doing the wrong thing, not having an identity as part of a group, losing connections, etc., fueling social motivation. Boys with autism can watch and learn social interaction, but are worse at it. Girls with autism watch, copy and learn how to mask their difficulties. Boys don't. Social awareness requires cognitive ability and observation skills. Girls with autism watch, copy and learn how to mask their difficulties. Girls watch, copy and learn how to mask their difficulties boys don't. Boys with autism can watch and learn social interaction, but are worse at it. Girls with autism likely have greater social awareness than boys. ASD girls have greater social awareness than boys. ASD boys more socially motivated than girls. Girls may be more socially motivated because they want a social identity. Girls with autism are likely more socially motivated than boys. ASD girls' desire to fit in, be part of groups, have friendships and relationships is fueling social motivation. Girls with autism want have a social identity. ASD girls fear not fitting in, saying or doing the wrong thing, not having an identity as part of a group, losing connections, etc., fueling social motivation. Social awareness requires cognitive ability and observation skills. Girls with autism watch, copy and learn how to mask their difficulties. Girls are more likely to be aware they are different and want social relationships, so copy others and mask their difficulties. Girls likely to have better social awareness than boys, but still vulnerable. The limited social awareness of girls with autism makes them vulnerable. Clinicians' have particular worries about the vulnerability of ASD girls. Extent of ASD girls social awareness. Girls with autism likely have greater social awareness, but still vulnerable. ASD boys' social awareness more variable. Gender differences in social responses/ability make gender differences in social awareness hard to judge. ASD girls have greater social awareness than ASD boys. Social awareness leads to awareness of difference, leads to social motivation, leads to wanting to fit in, leads to mimicking/copying, if able. Insight helps you ask for help.
Girls and boys with autism have similar language abilities. ASD girls are less likely than ASD boys to have early language problems but no difference when older. Similar language ability in ASD boys and ASD girls.

Social communication complex and sophisticated, but can be learned. ASD girls verbal and nonverbal communication ok in day to day situations, but cracks under pressure. ASD girls’ communication generally better than ASD boys. ASD girls’ expressive communication (verbal and non-verbal) ok.

Girls and boys with autism have the same communicative ability, but girls’ social communication often looks superficially better. Girls’ social communication is superficially ok, but breaks down when pushed. Girls can feel “off” due to difficulties with reciprocal communication. ASD girls can struggle with higher order pragmatics. ASD girls struggle with the subtleties of reciprocal, dynamic communication, and can feel ‘off’ when interacting with them.
Underlying social ability in girls and boys likely to be the same, but girls appear more social, and more actively trying to maintain friendships.

Girls more socially driven and try to engage socially. Boys less socially driven and often need help to maintain friendships.

Girls with autism independently try to engage socially but struggle, while boys have poorer friendships requiring more direct support.

Girls with autism are independently trying to engage socially but struggling to maintain friendships.

Boys and girls with autism have the same social ability, but girls appear more social.

Both boys and girls with autism can start to withdraw and become isolated.

Girls with autism have better emotional recognition and empathy, while boys have poorer friendships requiring more direct support.

Boys with autism have fewer and lower quality friendships, often needing support.

Girls with autism can be more controlling in social situations, while boys tend to be more relaxed.

ASD and NT girls have greater social ability, whereas ASD and NT boys have less social ability.

ASD and NT girls' social behaviour is different from ASD and NT boys' social behaviour.

ASD and NT girls have more complex social relationships, whereas ASD and NT boys' social interactions are simpler.

Girls with autism have better emotional recognition and empathy, while boys struggle with empathy.

ASD girls can be more controlling in social situations, while ASD boys tend to be more relaxed.

ASD girls struggle to keep and maintain friendships, often on the periphery or falling out.

ASD girls' friendships can be helpful.

ASD girls might have nurturing female friends.

ASD boys and girls seeking out low demand playmates.

Nature of friendships different between ASD boys and ASD girls.

Boys with autism have fewer and lower quality friendships, often needing support.

ASD boys might have mothering female friends.

ASD boys' friendships, if any, tend to be based on games (real or online) or adult maintained.

Boys and girls with autism have the same social ability, but girls appear more social.

Girls and boys with autism have similar levels of social ability.

Boys and girls with autism can start to withdraw and become isolated.

Girls with autism find it hard to fit in, while boys struggle to fit in.

ASD girls find it harder to fit in than ASD boys.

ASD boys don't fit in, while ASD girls find it harder to fit in.

ASD boys and ASD girls struggle to fit in social groups.

Limited differences in social ability between ASD boys and ASD girls.

ASD boys and ASD girls both struggle in social groups.

Limited differences in social ability between ASD boys and ASD girls.

ASD boys and ASD girls have the same social ability, but girls appear more social.

Girls more socially driven and try to engage socially. Boys less socially driven and often need help to maintain friendships.
While boys and girls have the same intensity in their special interests, girls' are often typical of other girls' interests, so harder to spot.

Girls tend to hide their special interests, and end up talking about them.

Interests of girls with autism are not unusual, so hard to spot.

Because girls' interests are not unusual, where as boys' interests can be, it's harder to spot the special interests of girls.

Interests of boys with autism can be unusual or socially acceptable.

Girls' special interests are social, cultural or creative, and not seen as unusual, making them hard to spot.

Interesting of boys with autism can be unusual or socially acceptable.

Girls' special interests are overt. ASD girls hide interest so don't talk about them/modulate/hide.

ASD girls' interests not obvious at first glance.

ASD girls' interests intense but not unusual/seem socially acceptable.

ASD boys' interests can be unusual/odd/memorable.

ASD boys tend to hide their special interests.

Overall, girls and boys likely to have equal intensity in their special interests.

ASD girls' interests pursued with intensity.

Intensive of special interest same for ASD boys and ASD girls.

ASD girls can have intensity without specific interest.

ASD boys not able to hide their interests, and end up talking about them.

ASD girls' interests included, as don't talk about them/modulate/hide.

ASD boys' interests pursuing interest intensity.

Girls' special interests providing an identity.

Girls might have an intensity of focus without a specific interest.

ASD boys' interests congruent with ASD girls.

Girls tend to hide their special interests, and end up talking about them.

ASD boys happy spending time on special interests and becoming proficient.

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ASD boys' interests pursuing interest intensity.

Girls' special interests providing an identity.
Girls and boys have the same imaginative ability and their play is equally affected by culture. Girls' imaginative play looks better superficially but actually copied/repetitive/scripted/inflexible. There is no gender difference in social imagination. ASD boys and ASD girls find it equally difficult to change play to fit others. Imaginative play of girls usually looks ok on the surface, but boys play is more clearly autistic. ASD girls appear more imaginative on the surface than ASD boys. Gender neutral (computer) games popular with ASD boys and ASD girls. ASD girls pretending to be animals, ASD boys taking on sci-fi/computer game roles.

ASD boys more likely to get fantasy/reality blurring than ASD girls. No gender differences in the likelihood of fantasy/reality blurring between ASD boys and ASD girls. ASD girls more likely to get fantasy/reality blurring than ASD boys.

Boys and girls with autism tend to play according to gender stereotypes. Fantasy worlds impact on social relationships.

Imagination more than making up stories. Motivation a difficulty in ASD, linked to imagination.
Girls and boys can be equally rigid, but apply that rigidity differently.

ASD girls and ASD boys equal in rigidity.

ASD girls less rigid than ASD boys.

ASD girls more rigid than ASD boys.

Rigidity linked to cognitive, social and anxiety difficulties.

Easier to see rigidity rather than social stuff in ASD girls.

ASD girls using rigid black and white thinking style to understand/work out social stuff.

ASD girls feeling sense of injustice against them.

ASD boys’ rigidity about repetitive behaviour/rituals/other keeping to standards.

ASD girls easier to redirect/better at following others agendas than ASD boys.

ASD girls possibly more perfectionistic.

ASD girls’ rigidity around routines/how things should be done/self following standards.

Quality of rigidity is different between ASD girls and ASD boys.

ASD girls’ rigidity can be masked/subtle.

Girls apply rigidity to themselves, boys apply it to others.

ASD girls using rigid black and white thinking style to understand/work out social stuff.

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Orientating model to superordinate theme “**Assessors need clinical experience and judgement to be able to apply criteria and measures, and uncover masking of difficulties**” on next page, with subsections of the theme on the following pages.
Assessors need clinical experience and judgement to be able to apply criteria and measures, and uncover masking of difficulties.

Clinicians need to gather and question evidence to build a full formulation, not just looking at what fits with autism.

Clinical judgement and experience is needed, particularly when assessing girls. This allows assessors to overrule diagnostic criteria, measures and uncover masking.

Diagnostic measures can be useful, but struggle to capture girls. They need to be carefully questioned and interpreted in the broader context of the assessment.

Gender bias exists in all information sources contributing to an assessment, so it is important to be aware of and consider the impact they might have.

Important to consider the impact of a diagnosis, and the diagnostic label before giving a diagnosis.

Diagnostic criteria an imperfect tool that captures part of a male presentation of autism. Needs clinical judgement to be applied effectively.

A good assessment requires in-depth information from multiple sources, especially when assessing girls.

While autism is the same in boys and girls, girls are better able to mask many of their difficulties with learned responses, needing the assessor to test for real intuitive understanding, particularly in social relationships.

While autism is the same in boys and girls, girls are better able to mask many of their difficulties with learned responses, needing the assessor to test for real intuitive understanding, particularly in social relationships.
Diagnostic criteria are imperfect tools that capture part of a male presentation of autism. Needs clinical judgement to be applied effectively.

DSM-5 is more flexible, takes a dimensional view and looks more at longevity and impact. DSM-5 is better and preferred.

Clinical judgement needs to apply/interpret/overrule diagnostic criteria.

DSM-4/ICD-10 has a narrow, classical, rigid view of ASD.

DSM-5 is flexible and preferred.

Diagnostic criteria are useful tools, but require clinical judgement to apply them.

Diagnostic criteria are useful as a framework/guide to thinking.

Diagnostic criteria are 'loose' and subject to interpretation.

No clear line between NT and ASD.

Criteria are a pick and mix; many criteria sufficient, but not all necessary/equal.

Diagnostic criteria fine for most children.

Diagnostic criteria not as good as formulation (longevity, functioning, support, etc).

Risk of mis/under-diagnosis if using criteria as a tick box exercise.

Experienced clinicians don’t use diagnostic criteria as a tick box exercise.

Autism is the same in girls and boys, but presents differently. As diagnostic criteria are based on boys, it is harder for girls to meet criteria.

High functioning kids not scoring up on social/communication bit of diagnostic criteria.

Diagnostic criteria based on ASD boys so easier for ASD boys/harder for ASD girls to meet criteria.

Classically autistic girls easy to meet criteria, harder for high functioning girls.

ASD girls presentation/interpretation of presentation not enough for diagnosis on RRBI section of diagnostic criteria.

ASD girls have the same core difficulties, meet the same criteria, but do so differently/more softly.

High functioning kids not scoring up on social/communication bit of diagnostic criteria.

High functioning (particularly) girls with ASD presentation not always captured/diagnosed by criteria.

High functioning kids not scoring up on the RRBI bit of criteria.

Separating criteria into male and female criteria is a bad idea.

Diagnostic criteria doesn’t fit well for ASD girls.

Core difficulties of ASD the same, but people might not tick every box, or do so at the same time in the same environment.

ASD girls trying socially. ASD boys not trying socially means harder for ASD girls/easier for ASD boys to meet criteria.

Diagnostic criteria missing things, such as anxiety, thinking style, executive functioning, etc.

You can hide ASD if you have average to high IQ.

There shouldn’t be variability in whether someone gets a diagnosis due to team or the child's development.

PDA sometimes (but not always) meeting ASD diagnostic criteria.

Diagnostic criteria can miss diagnosis.

The diagnostic criteria are not perfect, and miss aspects of the autism presentation.

Diagnostic criteria do not capture some aspects of autism and are not designed for girls.

Diagnostic criteria an imperfect tool that captures part of a male presentation of autism. Needs clinical judgement to be applied effectively.
A good assessment requires in-depth information from multiple sources, especially when assessing girls.

It is important to get a 360-degree view of a child during assessment, especially for girls.

In an assessment, it is important to have the opportunity to get to know someone over an extended period.

A good developmental history provides diagnostic information and helps you see if a girl is masking.

In an assessment, it is important to have the opportunity to get to know someone over an extended period.

History, observation, and reports from multiple sources needed to get 360-degree view required for Assessment (may not need ADOS).

Parental report important but might need to probe (but don’t dismiss!)

School/teacher reports of ASD girls require more probing/questioning to pin down ASD behaviours.

ASD girls more likely to present fine at school, but ‘decompress’ at home.

In an assessment, it is important to have the opportunity to get to know someone over an extended period.

Pressures for quick, high throughput pathway risks diagnostic reliability and quality.

Unsure what a good diagnostic pathway looks like, but involves ability to think more broadly and in-depth if needed.

Time to get to know someone important in diagnosis.

Diagnosis often clearer when you get to know someone over time.

Multi-disciplinary team important in assessment, especially for ASD girls.

A good developmental history provides diagnostic information and helps you see if a girl is masking.

A good developmental history means during observation and assessment you can focus on the nature of the behaviours, rather than trying to rule out other causes for the behaviour.

School observation always helpful but particularly for high functioning ASD girls/borderline cases.

ASD girls more likely to show inconsistent presentation across environments.

Focus of school observation is interaction with peers. ASD girls presentation in particular may be subtle.

Extended observation, in at least one unstructured environment important.

School observations allow you to see how a child functions in different environments.

History, observation, and reports from multiple sources needed to get 360-degree view required for Assessment (may not need ADOS).

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Time to get to know someone important in diagnosis.

Diagnosis often clearer when you get to know someone over time.

Multi-disciplinary team important in assessment, especially for ASD girls.
Have to work harder to unravel ASD girls' masking; They would be the same as boys if they didn't mask.

ASD girls (and some high-functioning ASD boys) likely to give surface/learned answers to their difficulties, requiring the assessor to establish whether they are learned or show true understanding.

ASD boys and older ASD girls are more likely to refuse to answer if don't know, ASD girls likely to try to answer.

Girls (and some boys) may make their difficulties in key areas during assessment, requiring the assessor to test their responses for real intuitive understanding.

The core of autism is the same for boys and girls, but presentation and understanding may differ.

ASD boys easier to diagnose, ASD girls harder to diagnose.

Friendships (starting/maintaining/making sense of reciprocity) important to evaluate when assessing for ASD.

ASD boys more likely to refuse to engage others in play, ASD girls more likely to show any special interests, and may need prompting to show them.

Girls with autism may label emotions, but struggle to talk about them properly.

ASD boys are able to understand fine social interaction, but need to be pushed to show them.

ASD girls are able to understand through social imagination tasks on the ADOS, as needed push them through the story, add contexts.

ASD girls (and high-functioning ASD boys) can imitate social interaction through play, assessment.

Need to consider if this is imaginative or rehearsed? Is he engaging the examiner properly?

ASD boys have social friendships difficulties obvious, ASD girls might have better descriptive/imaginary play.

ASD girls' friendships/social skills, "stifled"

Need to assess whether new social play affects others; boys play, girls only show surface understanding.

ASD girls use more, and other gestures on the ADOS than boys, especially with over-learned/emotional reasoning.

How to unpick HF ASD girls' (and HF boys') social treatment? Use social scenes of HF ASD.

High-functioning ASD girls (and high-functioning boys) have good social communication, key indicator of ASD in girls.

Language and social communication a key indicator of ASD in girls.

ASD girls likely to chat in assessment, easy to assure they are fine, need to really evaluate their challenge to see if true emotionality.
Important to consider the impact of a diagnosis, and the diagnostic label before giving a diagnosis.

Important to consider the impact of a diagnosis and whether it would be helpful.

Persons perspective on diagnosis and if they want a diagnosis important.

Diagnosis must be at the right time for the person and their family.

"Would a diagnosis be helpful" an important consideration.

Diagnosis not as useful as the support it accesses.

Diagnosis can reduce the persons and their family’s anxiety.

Diagnosis can help the person understand themselves.

Families prefer Aspergers or PDA diagnosis, and dislike an autism label (as in DSM-5).

Families get confused by different terminology and dislike labels that feel more impaired such as autism.

Clinicians having to explain different terminology (PDA, DSM-5) that families find confusing.

Families more likely to worry about sharing diagnosis.

No gender differences in post diagnostic support offered/uptake (although internalising/externalising will lead to differences in mental health support).

ASD girls more likely to worry about sharing diagnosis.
Gender bias exists in all information sources contributing to an assessment, so it is important to be aware of and consider the impact they might have.

The gender of both the assessor and the child will bias any assessment. Cannot avoid examiner gender bias. What is important is being aware of it and getting multiple perspectives.

Male assessors have lower standards (for social communication and interaction) than female assessors.

Male assessors find it harder to talk about ASD girls’ interests and give less social openings.

Males and females with ASD will react differently to male and female assessors.

Informants have gender biases and preconceptions that will influence their interpretation and reporting of gender biases.

Observers will interpret behaviour in a way that is influenced by their existing gender biases.
Diagnostic measures can be useful, but struggle to capture girls. They need to be carefully questioned and interpreted in the broader context of the assessment.

Girls can struggle to score up on measures, so it is important they are interpreted carefully as one part of an assessment.

The ADOS is a useful tool, but struggles to measure social insight, and other aspects of autism.

High functioning ASD girls (and boys) can pass ADOS through subtlety/learning, although might still have slightly unusual presentation.

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Diagnostic measures require interpretation, and their results should be questioned and considered in the broader context of the assessment.

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Need to reset neurotypcial benchmark on ADOS.

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ADOS a tool, not a diagnosis. ASD girls might not score up but still get a diagnosis.

ADOS and other measures not sensitive to ASD girls.

Pre-teen ASD girls not being picked up on ADOS, so coming back as teenagers and getting diagnosis.

Standardised measures important part of Assessment, but take with pinch of salt for ASD girls.

Disagreement over whether ADOS administered/scored differently for ASD boys/ASD girls.

ASD girls can score up ok on ADOS.

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Disagreement over whether ADOS administered/scored differently for ASD boys/ASD girls.

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High functioning ASD girls and boys' language subtle but structured assessment (ADOS) good at finding these.

High Functioning ASD girls and boys' language subtle but structured assessment (ADOS) good at finding these.

ADOS good, but limited on ability to measure insight/social relationship skill.

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ASD girls are able to give surface satisfactory answers to insight/social questions on the ADOS.

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High Functioning ASD girls (and high functioning boys) less likely to present with RRBs in ADOS.

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ADOS might not pick up on learned nature of social communication in ASD girls (eye contact, facial expressions, etc).

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ASD girls interests do not score up as abnormal on the ADOS.

ASD girls interests do not score up as abnormal on the ADOS.

ADOS won't pick up on emotion regulation difficulties, ADI will.

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ADOS boys and average functioning ASD girls caught out on social communication in ADOS.

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Discrepancy between ABAS and IQ indicator of possible ASD in high functioning cases.

Discrepancy between ABAS and IQ indicator of possible ASD in high functioning cases.

Need to question ADOS scores and understand why they did/did not score.

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ADOS one piece of the puzzle: cannot base diagnosis on ADOS alone.

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ADOS scoring subject to interpretation, need to interpret correctly (for girls).

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High Functioning ASD girls and boys' language subtle but structured assessment (ADOS) good at finding these.

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High Functioning ASD girls (and high functioning boys) less likely to present with RRBs in ADOS.

ADOS might not pick up on learned nature of social communication in ASD girls (eye contact, facial expressions, etc).

ADOS might not pick up on learned nature of social communication in ASD girls (eye contact, facial expressions, etc).

ASD girls interests do not score up as abnormal on the ADOS.

ASD girls interests do not score up as abnormal on the ADOS.

ADOS won't pick up on emotion regulation difficulties, ADI will.

ADOS won't pick up on emotion regulation difficulties, ADI will.

ADOS boys and average functioning ASD girls caught out on social communication in ADOS.

ADOS boys and average functioning ASD girls caught out on social communication in ADOS.

Discrepancy between ABAS and IQ indicator of possible ASD in high functioning cases.
Clinical judgement and experience is needed, particularly when assessing girls. This allows assessors to overrule diagnostic criteria, measures and uncover masking.

Social-emotional connectedness with a child leads clinicians to have a 'gut feeling' about autism.

Take gut feeling with caution.

Different professionals can disagree over ASD diagnosis; difference in perspectives/expertise?

Clinical judgement and experience is needed, particularly when assessing girls. This allows assessors to overrule diagnostic criteria, measures and uncover masking.

Experience of (girls with) autism helps assessors to know how what they are looking for and uncover masking.

People coming to Tier 3 getting diagnosis due to different criteria and being able to look at softer symptoms.

Clinical experience needed to unpick coping strategies and notice subtler presentations.

Clinical experience allows clinicians to question/overrule measures.

Clinical judgement can/should overrule measure or diagnostic criteria.

Clinical judgement and experience can and should overrule diagnostic criteria and measures.

Experience allows clinicians to get to know how ASD girls present.

Person can get diagnosis even when evidence poor/contradictory.

Clinical experience allows clinicians to question/overrule measures.
Clinicians need to gather and question evidence to build a full formulation, not just looking at what fits with autism. Clinicians must question the evidence informing an assessment, especially when assessing girls. Need to be particularly questioning of evidence when assessing ASD girls. Need to question results of structured assessments, including ADOS. Need to question all evidence informing assessment and investigate discrepancies. Informants and indirect info not ideal, and can be wrong/biased. Formulation needs to consider a child’s environment and all aspects of their development. Diagnostic formulation needs to consider environment, developmental opportunities and cultural influences. Diagnostic formulation needs to consider genetics, neurodevelopment and cognitive development. Diagnostic formulation needs to consider attachment, parenting, anxiety, emotional regulation strategies and trans-diagnostic categories (internalising/externalising). Clinicians need to formulate with an open mind, considering other diagnoses, not just autism. Important to consider other diagnoses/is diagnosis needed. Lots of things (attachment, LD, etc) can look like ASD. Diagnostic formulation should be needs focused. Formulation not a tick box “can I explain it this way” exercise.
Appendix 2M: Condensed model from stage 7

Due to the complexity of this model, it is not possible to show the entire model on one page. A PDF showing the whole of this model can be found at www.tinyurl.com/JMThesis, and opened using the password “Wing1979”

Note that themes are indicated by **bold**.

The model consists of five superordinate themes, each of which is presented individually on the following five pages.
1. Girls and boys with autism are exactly the same but have completely different presentations.

1.1 Girls and boys often have mental health problems, but cope differently.

1.1.1 Girls are more likely to have mental health problems, but cope differently.

1.1.2 Girls try to cope, affecting their mental health.

1.1.3 Girls are more likely to engage successfully in therapy.

1.1.4 People with autism likely to have mental health problems.

1.1.5 Girls may present differently, but as the complexity of social relationships increases their presentations become similar.

1.2 Younger girls and boys may present differently, but as the complexity of social relationships increases their presentations become similar.

1.2.1 Boys and girls initially present differently, but their presentations become similar over time.

1.2.2 There is a social-developmental jump which girls are more likely to struggle with, making their social difficulties more obvious.

1.2.3 Children with autism struggle with the transition from primary to secondary school.

1.3 Girls are more likely to be aware they are different and want social relationships, so copy others and mask their difficulties.

1.3.1 Girls likely to have better social awareness than boys, but still vulnerable.

1.3.2 Girls watch, copy and learn how to mask their difficulties; boys don't.

1.3.3 Girls may be more socially motivated because they want a social identity.

1.4 Girls and boys with autism have similar language abilities.

1.4.1 Girls and boys with autism have similar language abilities.

1.4.2 Girls' social communication is superficially ok, but breaks down when pushed.

1.4.3 Girls can feel “off” due to difficulties with reciprocal communication.

1.5 Girls and boys can be equally rigid, but apply that rigidity differently.

1.5.1 Girls and boys can be equally rigid.

1.5.2 Girls apply rigidity to themselves, boys apply it to others.

1.6 Girls and boys have the same imaginative ability, but girls' imaginative play looks superficially better.

1.6.1 Girls and boys have the same imaginative ability, but girls' imaginative play looks superficially better.

1.6.2 Boys and girls with autism tend to play according to gender stereotypes.

1.7 While boys and girls have the same intensity in their special interests, girls' are often typical of other girls' interests, so harder to spot.

1.7.1 Girls tend to hide their special interests.

1.7.2 Overall, girls and boys likely to have equal intensity in their special interests.

1.7.3 Girls might have an intensity of focus without a specific interest.

1.7.4 Girls' special interests are social, cultural or creative, and not seen as unusual, making them hard to spot.

1.8 Underlying social ability in girls and boys with autism are the same, but girls appear more social, and more actively trying to maintain friendships.

1.8.1 Girls more socially driven and try to engage socially. Boys less socially driven and often need help to maintain friendships.

1.8.2 Boys and girls with autism have the same social ability, but girls appear more social.

1.8.3 Both boys and girls with autism can start to withdraw socially and become isolated.

1.8.4 Girls with autism have better emotional recognition and empathy.

1.9 Girls and boys with autism have the same communicative ability, but girls' social communication often looks superficially better.

1.9.1 Girls and boys with autism have similar language abilities.

1.9.2 Girls with autism have better emotional recognition and empathy.

1.9.3 Girls with autism have better emotional recognition and empathy.

1.9.4 Girls with autism have better emotional recognition and empathy.

1.9.5 Girls with autism have better emotional recognition and empathy.

1.9.6 Girls with autism have better emotional recognition and empathy.

1.9.7 Girls with autism have better emotional recognition and empathy.
2. Assessors need clinical experience and judgement to be able to apply criteria and measures, and uncover masking of difficulties.

2.1 Diagnostic criteria are imperfect tools that capture part of a male presentation of autism. Needs clinical judgement to be applied effectively.

2.1.1 DSM 5 is flexible and preferred.

2.1.2 Diagnostic criteria are useful tools, but require clinical judgement to apply them.

2.1.3 Diagnostic criteria do not capture some aspects of autism and not designed for girls.

2.2 A good assessment requires in-depth information from multiple sources, especially when assessing girls.

2.2.1 It is important to get a 360 degree view of a child during assessment, especially for girls.

2.2.2 In an assessment it is important to have the opportunity to get to know someone over an extended period.

2.2.3 A good developmental history provides diagnostic information and helps you see if a girl is masking.

2.2.4 School observations allow you to see how a child functions in different environments.

2.3 While autism is the same in boys and girls, girls can better mask many of their difficulties with learned responses, requiring the assessor to test their responses for real intuitive understanding, particularly in social relationships.

2.3.1 Seeing if a child understands and demonstrates how to relate socially is key.

2.3.2 While autism is the same in girls and boys, girls can mask their difficulties in key areas during assessment, requiring the assessor to test their responses for real intuitive understanding.

2.3.3 Girls may mask their difficulties in key areas during assessment, requiring the assessor to test their responses for real intuitive understanding.

2.4 While autism is the same in boys and girls, girls are better able to mask many of their difficulties with learned responses, requiring the assessor to test for real intuitive understanding, particularly in social relationships.

2.4.1 Important to consider the impact of a diagnosis and whether it would be helpful.

2.4.2 Families get confused by different terminology and dislike labels that feel more impaired such as autism.

2.5 Clinicians need to gather and question evidence to build a full formulation, not just looking at what fits with autism.

2.5.1 Clinicians must question the evidence informing an assessment, especially when assessing girls.

2.5.2 Formulation needs to consider a child’s environment and all aspects of their development.

2.5.3 Clinicians need to formulate with an open mind, considering other diagnoses, not just autism.

2.6 Clinical judgement and experience is needed, particularly when assessing girls. This allows assessors to overrule diagnostic criteria, measures and uncover masking.

2.6.1 Social-emotional connectedness with a child leads clinicians to have a ‘gut feeling’ about autism.

2.6.2 Clinical judgement and experience can and should overrule diagnostic criteria and measures.

2.6.3 Experience of (girls with) autism helps assessors to know how what they are looking for and uncover masking.

2.7 Diagnostic measures can be useful, but struggle to capture girls. They need to be carefully questioned and interpreted in the broader context of the assessment.

2.7.1 Girls can struggle to score up on measures, so it is important they are interpreted carefully as one part of an assessment.

2.7.2 Diagnostic measures require interpretation, and their results should be questioned and considered in the broader context of the assessment.

2.7.3 The ADOS is a useful tool, but struggles to measure social insight, and other aspects of autism.

2.8 Gender bias exists in all information sources contributing to an assessment, so it is important to be aware of and consider the impact they might have.

2.8.1 The gender of both the assessor and the child will bias any assessment.
3. Social interaction and communication is the essential "core" of autism.

3.1 Girls have some protection against autism.

3.2 People with autism have difficulties with sensory sensitivities, social communication, social interaction and a different thinking style.

3.3 Girls have some protection against autism, so are more subtle in presentation.

3.3.1 Girls have some protection against autism.

3.3.2 Presentation of girls more subtle and they avoid drawing attention to themselves.

3.4 Autism is defined by the triad of impairments. This is a useful tool, but does not capture everything about autism.

3.4.1 The triad forms the basis of diagnosis, but does not capture everything about autism.

3.4.2 While the dyad is a step forward in criteria, the triad is more useful.

3.5 People with autism present very differently, but gender differences can be seen in those with high functioning autism.

3.6 Autism is one disorder that can be caused by multiple factors.
 Girls with autism are accurately diagnosed, but not getting referred for assessment until later, often after being in mental health services.

Boys are picked up young due to their behaviour. Girls are picked up later via mental health services, but autism often goes unrecognised for some time.

Girls are presenting to mental health services, but the underlying autism is not identified.

Boys with autism get ADHD or conduct diagnoses, girls get mental health diagnoses.

4.1 Girls are now accurately diagnosed, but still under diagnosed.

4.2 Autism has comorbidities and conceptual overlap with other disorders.

4.3 Boys are picked up for diagnosis young due to their behaviour.
5. Autism is defined and modified by our culture. Because autism is defined as being for boys, girls find it harder to be picked up for assessment and to get support.

5.3 People have different expectations of girls and boys with autism, leading to differences in support

5.3.1 Autism is culturally acceptable for boys, but not for girls.

5.4 People do not know how autism is different in girls, meaning they are not picked up nor considered for assessment

5.4.1 Schools, parents and professionals lack awareness of how autism is different in girls and do not look out for it.

5.4.2 Professionals are not used to assessing girls for autism, so prefer to consider other explanations
Appendix 2N: Thesis proposal form

Appendix 2N is presented on the following 29 pages
Once completed to the satisfaction of both thesis supervisors, submit electronically via Learn as a Word file with the filename YourExamNumber_DateSubmitted_R1 (e.g. B011101_24June12_R1.doc)

D.CLIN. PSYCHOL.
UNIVERSITY OF EDINBURGH / NHS (SCOTLAND)
TRAINING PROGRAMME

Front sheet / Title Page for Submitted Academic Work

TRAINEE NAME: Joshua Muggleton

TITLE OF SUBMISSION: Thesis Proposal

COURSE SUBMITTED FOR (please tick relevant box):

<table>
<thead>
<tr>
<th></th>
<th>CP1</th>
<th>CP2</th>
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<tr>
<td>Case conceptualisation (CP1 and CP2)</td>
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<td>Case study (only for those starting pre 2009)</td>
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<td>Essay questions (only for those starting pre 2009)</td>
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<td>OA/Neuro Child</td>
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Research proposal (R1)

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Small scale research project (R2)

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Small scale research project 2 (only for those starting pre 2009)

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Thesis

Submitted in part fulfilment of the degree of doctorate in Clinical Psychology at the University of Edinburgh

Date Submitted: 15/7/15
D. Clin. Psychol. Declaration of own work

This sheet must be filled in (each box ticked to show that the condition has been met), signed and dated, and included with all assignments - work will not be marked unless this is done

Name: Joshua Muggleton

Assessed work: Case Conceptualisation Research proposal Case Study
SSRP Essay Question Paper Thesis

(please circle/delete as applicable)

Title of work: Thesis Proposal

I confirm that all this work is my own except where indicated, and that I have:

- Read and understood the Plagiarism Rules and Regulations ✓
- Composed and undertaken the work myself ✓
- Clearly referenced/listed all sources as appropriate ✓
- Referenced and put in inverted commas any quoted text of more than three words (from books, web, etc) ✓
- Given the sources of all pictures, data etc. that are not my own ✓
- Not made undue use of essay(s) of any other student(s) either past or present (or where used, this has been referenced appropriately) ✓
- Not sought or used the help of any external professional agencies for the work (or where used, this has been referenced appropriately) ✓
- Not submitted the work for any other degree or professional qualification except
as specified
✓

• Acknowledged in appropriate places any help that I have received from others
  (e.g. fellow students, technicians, statisticians, external sources)
✓

• Complied with other plagiarism criteria specified in the Programme Handbook
✓

• I understand that any false claim for this work will be penalised in accordance with
  the University regulations
✓

• (For R2 & Thesis) Received ethical approval from the University of Edinburgh,
  School of Health

☐

OR

• (For R2 & Thesis) Received ethical approval from an approved external body and
  registered this application and confirmation of approval with the University of
  Edinburgh’s School of Health’s ethical committee

☐

Signature Joshua Muggleton   Date ...15/7/15

Please note:

a) If you need further guidance on plagiarism, you can:
  i/ Speak to your personal tutor or supervisor
  ii/ View university regulations at http://www.ed.ac.uk/schools-departments/academic-services/policies-regulations

b) Referencing for most assessed work should be in the format of the BPS style guide, which is freely available from the BPS web site
Doctorate in Clinical Psychology


This form should be completed and submitted as the assessment for Research 1. It will then be reviewed by a member of the academic team and will receive a grade and detailed feedback. The feedback will include an evaluation of the viability of the project and any recommendations. If there are significant concerns about viability, the project will be flagged to the research director and the research committee will decide whether the project can proceed in its current form.

Provisional Thesis Title: A qualitative study of highly experienced clinical psychologists’ conceptions of autism and gender differences in presentation and diagnosis

Exam number: B066823

Allocated Thesis Project Supervisors

Clinical Katrina Johnston, Clinical Psychologist, NHS Fife

Academic 1 Ken MacMahon, Senior Lecturer in Clinical Psychology, University of Edinburgh

Academic 2 (where applicable)

Others involved as part of project team (if applicable)

Proposed setting(s): Online and in meeting rooms (not in clinical settings)
(Where research will be carried out)

Anticipated Month & Year of Submission of Thesis: 1st May
(please delete as applicable)

2015 2016

2017

(Must be in final year for full time trainees. For flexible trainees, the month & year of submission will depend on their Individual Training and Development Plan. Trainees from 2011 intake onwards must submit in May, trainees who started in 2010 or earlier are advised to submit in May to reduce potential for HPC registration difficulties)
Please Note: Whilst this is not an ethics review process, where questions have some similarities to questions contained in the NHS IRAS Research Ethics form, the corresponding IRAS question numbers are given in parentheses. This is intended to facilitate completion of NHS ethics where such approval is needed.

Version (date): 15/7/15

Introduction
1) Please provide a brief critical review of relevant literature, which should clearly demonstrate the rationale and scientific justification for the research. (Relevant to IRAS A12)

(Guideline 1000 to 1500 words)

The term “Autism Spectrum Disorder” (ASD) is, arguably, a diagnostic label in a state of flux. Broadly and historically, it refers to a constellation of difficulties related to social interaction, verbal and nonverbal communication, and restrictive and repetitive behaviours and interests (RRBs) (Wing & Gould, 1979). However, differences in executive functioning (Hill, 2004), theory of mind (Baron-Cohen, Leslie & Frith, 1985), information processing (Frith & Happe, 1994), and sensory integration (Rogers & Ozonoff, 2005), have been identified as possible underlying mechanisms to these difficulties. Like many psychological disorders, it is identified by its symptoms rather than its cause, although attempts to find a cause have repeatedly been made (e.g Baron-Cohen, Leslie, & Frith, 1985; Frith and Happe, 1994; Baron-Cohen, 2002). However, it is the heterogeneity in the severity, number, frequency and presentation of these symptoms that makes defining the disorder particularly difficult.

Diagnostic criteria for ASD rely on the observation and classification of complex behaviours. For example, criterion A1 of the DSM-V states:

“Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect’ to failure to initiate or respond to social interactions.”

Although the criterion is stated as, “deficits in social-emotional reciprocity,” and examples are given of these, it is not an exhaustive list. Therefore the clinician is required to identify whether
any of the innumerable behaviours a client presents with meets this description, and whether the behaviour is sufficiently “deficient” to meet the diagnostic criteria. Diagnostic tools, such as the Diagnostic Interview for Social Communication Disorders (DISCO, Wing et al., 2002) and Autism Diagnostic Observation Schedule (ADOS-R, Lord et al., 2000) have been developed to help clinicians do this, but still require clinical judgement to use, and only serve to guide, rather than make a diagnosis.

Although there are substantial individual differences, males and females differ in their behaviour at a population level. For example, males and females differ in aggression (Archer, 2004), empathy (Baron-Cohen & Wheelwright, 2004), and non-verbal communication of emotion (Hall, Carter & Horgan, 2000). Wood and Egly (2002) argue these behavioural differences are a result of a combination of biology (e.g. hormone levels; Rowe et al., 2004), and social influences (different parenting styles for boys and girls, societal expectations; Tenebaum & Leaper, 2003). Given those with and without ASD share a similar biological makeup and social environment, it is unsurprising that males and females with ASD also show statistical (Many et al., 2011) and anecdotal differences in their behaviour (Attwood, 2007; Kopp & Gillberg, 2011). For example, Lai et al. (2015) collated a list of behaviours that anecdotally appear to be different in girls with ASDs (see Table 1).

Table 1: Anecdotal differences in behaviour between males and females with ASD. Adapted from Lai et al. (2015).

<table>
<thead>
<tr>
<th>DOMAIN</th>
<th>Characteristics more often present in females than males</th>
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<tbody>
<tr>
<td>Social Interaction</td>
<td>Greater awareness of the need for social interaction</td>
</tr>
<tr>
<td></td>
<td>Desire to interact with others</td>
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<td></td>
<td>Passivity (a “loner”), often perceived as “just being shy”.</td>
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<td></td>
<td>Tendency to imitate others (copy, mimic, or mask), in social interactions, which may be exhausting</td>
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<td></td>
<td>Tendency to “camouflage” difficulties by masking and/or developing compensatory strategies</td>
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<td></td>
<td>One or few close friendships</td>
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<td></td>
<td>Tendency to be “mothered” in a peer group in primary school, but often bullied in secondary school</td>
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<tr>
<td>Communication</td>
<td>Better linguistic abilities developmentally</td>
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<tr>
<td>Better imagination (fantasizes and escapes into fiction and pretend play, but is prone to being nonreciprocal, scripted, and overly controlled)</td>
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<td></td>
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<tr>
<td>Restricted, repetitive patterns of behaviour, interest or activities</td>
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<tr>
<td>Restricted interests tend to involve people/animals, rather than objects/things (e.g., animals, soap operas, celebrities, pop music, fashion, horses, pets, and literature), which may be less recognized as related to autism</td>
<td></td>
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<tr>
<td>Other</td>
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<tr>
<td>Tendency to be perfectionistic, very determined</td>
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<tr>
<td>Tendency to be controlling (in play with peers)</td>
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<td>High (passive) demand avoidance</td>
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<tr>
<td>Tendency to have episodes of eating problems</td>
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These gender differences create additional challenges for clinicians judging whether behaviours meet diagnostic criteria. For example, as (in general) females score higher on empathy measures (Baron-Cohen & Wheelwright, 2004), and show greater ability to read non-verbal communication of emotion (Hall & Matsumoto, 2004) should less severe “deficits” in social interaction, relative to boys, be sufficient for diagnosing girls? Is there a qualitative population-level difference in the social interaction between ASD and non-ASD females, in which case, what does it look like, and does it show on an individual level? Diagnostic tools such as the ADOS and DISCO do not have separate algorithms for males and females, relying on clinicians’ judgement to factor in any such differences in gender presentation either at scoring or interpretation, despite tools such as the Connors’ Parent Rating Scale (CPRS, Connors, 1989) having separate algorithms for males and females with Attention Deficit Hyperactivity Disorder.

Gaining an understanding of gender differences in ASD is further exacerbated by the gender bias within studies into this condition. Since Kanner (1943) and Asperger’s (1944) original descriptions of ASD, males have substantially outnumbered females. Currently, estimates of the male:female ratio in ASDs are 4.3:1 (Fombonne, 2003; Fombonne, 2005; Fombonne, 2007). While there is likely an underlying bias towards males in the population (Attwood, 2006), research on ASDs is typically male biased, and rarely makes male:female comparisons (Watkins,
The limited numbers of females included within research may limit our understanding of this condition in females.

If research is based on a mostly male sample, the behavioural picture developed will have more masculine behaviours. This could lead both research, and the diagnostic criteria which they inform, to be biased towards examining male behaviours and presentations of ASD, discounting female ASD behaviours. Similarly, Koenig and Tsatsanis (2005) have highlighted that many diagnostic tools, such as the DISCO and ADOS, are validated on a predominantly male sample, with no or little exploration of gender differences in scoring or validity. These factors could lead to fewer females being diagnosed due to the criteria being based on different population, therefore perpetuating the male preponderance in the population.

Secondly, it is worth noting that the original descriptions of children with ASD were heavily biased toward males. While this bias may reflect underlying population ratios, it may have also influenced researcher and clinician expectations that ASD is a predominantly male condition. This may lead clinicians to compare a female’s presenting behaviour with prototypical male behaviours, and attribute the difference due to the presence/absence of ASD, rather than to gender differences. It may also lead to clinicians feeling reluctant to link feminine behaviours with the behavioural description of ASD as they are less common, and therefore they feel less confident in classifying these behaviours as clinically significant.

While there is likely an underlying gender bias with ASDs, if there is a gender bias at diagnosis, then the gender bias seen in the population could be self-perpetuating, and potentially exaggerated. This could make it harder for females to be diagnosed, and lead many females with ASD to go undiagnosed and unsupported. Supporting this, Dworzynski et al. (2012) and Russell et al. (2010), found that girls were significantly less likely to meet diagnostic criteria than boys when presenting with the same number of autistic-like traits. Equally, females are diagnosed significantly later than their male counterparts (Begeer et al., 2012; Giarelli et al., 2010). Therefore, given the value to quality of life of early diagnosis and intervention (Koegel et al., 2014), females with ASD may miss out on support available to their diagnosed peers.
Finally, the bias in research could lead to an inaccurate picture of ASDs, impeding future research on the condition.

Given the implications of this possible gender bias, research examining if and how girls present differently is required. Lai et al. (2015) suggest a research framework for understanding the differences between gender presentations in ASD, the first of which is creating accurate definitions and diagnostic criteria for ASD. To do this, they highlight the need for a broad construct definition of ASD, free from gender differences, narrower constructs relating to areas of differences in ASD (e.g. attention to detail, nonverbal communication, etc.), and behavioural examples of each aspect of the definition. They argue that gender differences should only be present at the level of narrow constructs and behavioural exemplars, and that research on gender differences should therefore focus on these levels. However this assumes that the broad construct of ASD is already gender neutral. If, as outlined earlier, females have been systematically under diagnosed and underrepresented within the research, then the broad conception of ASD may be biased. Therefore, research needs to revisit this broad construction to create a gender-neutral definition before narrow constructs and behavioural exemplars can be examined. Not doing so risks creating a male-only definition, with a ‘special case’ for females, perpetuating the problem.

Given the risk of a gender bias in the existing research and diagnostic criteria, any investigation into the definition and presentation of ASD will need to do so in a way that is not reliant on the existing diagnostic criteria. Quantitative methods rely on the measurement of pre-defined areas, based on the current conception of ASD, creating circularity. Therefore, a qualitative approach is required.

This study aims to investigate the definition and presentation of ASD, and the gender differences therein. In order to allow for new behaviours and constructs to be identified, a qualitative approach will be used. Clinicians diagnosing ASD will have been trained to do so according to diagnostic criteria, diagnostic tools, and research, all of which are at risk of male bias. However, highly experienced clinicians may have developed their own understanding of ASD that goes beyond the diagnostic criteria and tools, and learned how males and females
present differently. By interviewing clinical psychologists with a great deal of experience in diagnosing children with ASD, this project hopes to capture this understanding to produce a more ecologically valid conception of what ASD is. Through semi-structured interviews, this conception will be explored, with particular reference to how it incorporates gender differences at the narrow construct level, and how gender differences present at the behavioural phenotype level.

**Research Questions / Objectives:**

(Keep these focused and concise, with a maximum of five research questions).

2) What is the principal research question / objective? (IRAS A10)

1 – How do clinicians conceptualise Autism Spectrum Disorders, and gender differences in presentation?

3) What are the secondary research questions / objectives if applicable? (IRAS A11)

2 – What key differences between girls and boys do clinicians note when making an assessment for an Autism Spectrum Disorder?

3 – How does the diagnostic process for Autism Spectrum Disorder differ between girls and boys?

4 – Do clinicians’ conceptualisations of Autism Spectrum Disorder match standard diagnostic criteria of ICD-10 and DSM-V?

**Methodology**

4) Please give a full summary of your design and methodology. It should be clear exactly what will happen at each stage of the project. (Relevant to IRAS A13)

*Research design*

A semi-structured interview schedule will be constructed by the researcher and supervisors, using open-ended questions, as recommended by Kvale and Brinkmann (2009). The questions will aim to explore the broad construct of ASD, areas of gender differences within ASD (narrow constructs), evidenced with case and behavioural exemplars. The semi-structured interview process will allow for follow up questions, and reflections. Transcripts of the interviews will be
analysed using Thematic Analysis, based on guidance from Braun and Clarke (2006). Thematic analysis will allow for patterns in participants’ perspectives to be identified, explored in relation to each other and existing theory, and for an ecologically valid description of ASD to be generated.

**Participants**
10-14 participants will be recruited using non-probabilistic, purposive sampling. This will allow for the creation of a sample with significant and broad experience of autism in children. To this end, researchers will target highly experienced clinical psychologists, who have diagnosed many cases of ASD in both males and females. Participant recruitment will focus on clinical psychologists working for the NHS in the UK, but may include clinical psychologists in other settings.

**Procedure**
E-mails will be sent to heads of services that provide diagnostic assessments of ASD in children. Information regarding the study will be given, and a request to recruit clinicians from their services will be made. If this is granted, contact will be made with individual clinicians, providing them with information about the project, and asking if they would be willing to be placed on a list of prospective participants to be contacted in the future to take part. Services with clinicians that might meet inclusion criteria will be identified through personal contacts, public databases of ASD diagnostic services, research publications, and their head of service. The researcher and supervisors will then discuss the relative experience, perspectives and merits of all prospective participants, and select the 14 participants likely to provide the greatest depth and variety of experience.

Participants will be contacted via e-mail and asked if they would still like to take part in the study, and provided with further information on the study and the types of questions they may be asked. If they consent, they will be asked to attend an interview at a time and place convenient to them. This will primarily be done in person, but may be done via Skype if required. While Skype is a new medium for qualitative data gathering, it has been used successfully in research (Hanna, 2012). Although the dynamic of the interview changes when
using Skype (such as greater trust, reduced control over the environment, and distraction with one’s own image), it has been evaluated as a suitable research tool (Bertand & Bourdeau, 2012), and guidance has been produced (ibid., King & Horrocks, 2010). Interviews will last 60-90 minutes and will be audio recorded and transcribed verbatim by the researcher.

5) Please list the principal inclusion and exclusion criteria (IRAS A17-1 and A17-2)

**Inclusion criteria**

1. Qualified Clinical Psychologist registered with the HCPC or their national equivalent
2. Have substantive experience in diagnosing children (<18 years) with ASDs.

Note: “substantive experience” is a deliberately broad term, which relies largely on the personal self-evaluation of prospective participants, and the researcher’s opinion. This was chosen deliberately as quantifying a number of diagnostic cases may not necessarily yield a high degree of experience. For example, working with a comparatively small number of very complex/borderline cases may give more information than administering a screening questionnaire to a large number of relatively straightforward diagnostic cases.

Note: It was decided to limit analysis to examples of diagnosing those under 18. It was felt that child and adult presentations would be qualitatively different, and increase the heterogeneity of the data. Given that people are most frequently diagnosed in childhood, and that early accurate diagnosis allows for earlier supportive interventions, it was decided to focus on child presentations only. While participants may have worked with, or be actively working with, adults with ASD, they must have significant experience with under 18s with ASD to draw upon, as examples given during interviews based on adult presentations will be excluded from the analysis.

**Exclusion criteria**

1. Experience is based predominantly with adults with ASD
2. Experience is based predominantly on people with ASD and a comorbid Learning Disability

3. Limited experience diagnosing or working with girls with ASD

4. A high number of colleagues from the same service also taking part in the study

6) How will data be collected?
If quantitative, list proposed measures and justify the use of these measures. If qualitative, explain how data will be collected giving reasonable detail. (Don’t just say ‘by interviews’)

Interviews will be audio recorded and transcribed verbatim by the researcher. During transcription any information identifying either the participant or their clients will be removed. Similarly, examples using adults with ASD will be transcribed but marked as such and excluded from the analysis.

Sample Size
7) What sample size is needed for the research and how did you determine this? For quantitative projects, outline the relevant Power calculations and the rationale for assuming given effect sizes. For qualitative projects, outline your reasoning for assuming that this sample size will be sufficient to address the study’s aims. (IRAS A59 and A60)

Theoretical data saturation, the point at which new interviews add nothing substantive to the analysis, is defined as the gold standard for qualitative research (Morse et al., 1995). Guest, Bunce and Johnson (2006) analysed code-books from a study using thematic analysis with 60 participants across two different contexts in an attempt to determine the rate of data saturation. In Guest et al. at 12 participants, 92% of codes were captured, with 58% of code revisions made. Equally, at this point, the consistency of codes between interviews was good (0.7 measured with Chronbach’s alpha). We therefore assume that 10-14 will be sufficient to provide an analysis with enough breadth and depth to be meaningful and capture all key elements, given the pragmatic constraints of participant availability and the resource intensive nature of qualitative research.

8) Outline reasons for your confidence in being able to achieve a sample of at least this size. (e.g. by giving details of size of known available sample(s),
percentage of this type of sample that typically participate in such studies, opinions of relevant individuals working in that area)

In March 2015, the author and supervisors started to determine the potential for recruitment to the study by providing a broad outline of the proposed study to clinicians in the field. To date, we have 10 people who have confirmed they would be willing to consider participation in the study when ethical permission to begin recruitment has been granted. Additionally, the local head of CAMHS has agreed to forward information to other CAMHS heads in Scotland. We are therefore confident in our ability to achieve 14 interviews.

**Analysis**

9) Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives. (IRAS A62)

Data will be analysed using Thematic Analysis. Our primary research question, “How do clinicians conceptualise Autism Spectrum Disorders, and gender differences in presentation?” requires the development of a conceptual model of ASD, in relation to existing theories. Using thematic analysis allows for a realist approach, and the assumption that there are knowable, definable, broad and narrow constructs which collectively define ASD and the behaviours therein. It also allows for codes to be generated semantically, allowing for a description of clinicians’ conceptualisations, rather than an attempt at understanding where these conceptualisations come from. Finally, it allows for a theoretical approach, allowing for clinicians’ responses, and the conceptualisation they create to be explicitly linked with existing theories of ASD.

Braun and Clarke (2006) have provided comprehensive guidance on how to conduct Thematic Analysis. They outline six phases of analysis, which this study will follow:

1) **Familiarising yourself with the data:** immersing oneself in the data by reading and re-reading (or listening) to transcripts in an active way, while making broad notes on ideas for codes
2) **Generating initial codes**: detailed coding each transcript according to interesting features of the data, in a way that describes the data in a concise way, without losing the richness of the data.

3) **Searching for themes**: collecting codes together into themes – broad descriptions which the analyst defines to attempt to explain what is going on.

4) **Reviewing themes**: ensuring each theme is appropriately defined, and not better subsumed into another theme or split. This includes arranging themes into subordinate and superordinate themes.

5) **Defining and naming themes**: Analysing the data within each theme to generate a refined definition for the theme that places it in a narrative of the data that is meaningful to the research question.

6) **Producing the report**: Producing a written narrative that ties together important, relevant and/or interesting themes within the data in a way which allows the reader to understand the different aspects of the data. This will also embed the research in a broader theoretical and practical context.

In addition to conducting the analysis, Cohen and Crabtree (2008) identified 7 criteria for good qualitative research. These guidelines are set out below, with descriptions of how this study will meet each element to ensure the quality of the analysis.

1. **Carrying out ethical research.** The study will be subjected to ethical review by the University of Edinburgh. In addition, while ethical approval is not required by the local NREC, an ethics committee will also review the study to ensure the study has been ethically approved by an external source.

2. **Importance of the research.** As outlined above, this research will add important evidence to the debate on how girls with ASD present differently. It is hoped this will allow for better, earlier diagnosis, creating opportunities for early interventions. In addition, it may allow for a better understanding and description of ASD, providing a foundation for future research to create more representative samples.

3. **Clarity and coherence of the research.** The study will be written up in a journal format under regular supervision. It will be submitted as part of a D.Clin.Psychol thesis, and
subjected to internal and external marking, including a viva, after which it will be submitted to a peer-reviewed journal. This provides numerous opportunities for feedback from multiple sources to ensure the research is clear to the reader.

4. **Appropriate and rigours methods.** In creating this proposal, and through supervision, various methods of data collection and analysis have been considered. Through this thesis proposal being reviewed, the appropriateness and rigor of the methods will be evaluated, ensuring this criterion is met.

5. **Importance of reflexivity/attending to researcher bias.** Braun and Clark (2006) view researcher bias as an integral part of the analysis, as it is the researcher’s creativity that creates codes and themes. However, the study will include a statement of the researchers pre-existing knowledge and biases to clarify how the analysis may be influenced. In addition, to minimise undue bias, sample analyses and extracts will be presented in supervision to ensure consistency, and that the analyses have not been unduly influenced. Finally, the researcher will keep a reflective diary to note their perceptions, biases and processes, and how they may have impacted the analysis.

6. **Establishing validity.** According to Cohen and Crabtree, validity requires “a rich, substantive account with strong evidences for inferences and conclusions”. The researcher will therefore draw in prior experience of conducting qualitative research, supervision, and examples of good practice to ensure that the evidence outlined produces a suitably rich and substantive account. Similarly, supervisors will be encouraged to question conclusions and inferences the researcher makes in the analysis, to ensure that it is the most logical, plausible and accurate representation of the data possible.

7. **Verification and reliability.** Cohen and Crabtree suggest that verification and reliability can be improved through triangulation, peer review/debriefing, external audits, and member checking. Triangulation will be achieved by ensuring that participants are selected from different locations, teams, and settings, ensuring a variety of approaches and perspectives. While peer review will not be external as Cohen and Crabtree recommend, the researcher will regularly receive supervision to explore and debate analysis, and debrief from interviews to ensure both agreement in the analysis, and that implicit aspects of the analysis are made explicit and evaluated. Similarly, samples
of the analysis and relevant extracts will be submitted for internal audit within the team. Additionally, the full analysis (although, to protect confidentiality, not the original transcripts) will be made available in the final thesis, to allow examiners to audit the analysis. Finally, participants will be asked to review and comment on the analysis of their transcripts, within the time limitations of the thesis.
Once completed to the satisfaction of both thesis supervisors, submit electronically via Learn as a Word file with the filename `YourExamNumber_DateSubmitted_R1` (e.g., B011101_24June12_R1.doc).

### Project Management: Timetable

<table>
<thead>
<tr>
<th>2015</th>
<th>2016</th>
<th>2017</th>
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#### Key Stages:
- **Research**
  - Thesis Proposal
  - Systematic Review (Lit search)
  - Systematic Review (write up)
  - Ethics and documentation
- **Data Scale**
  - Interviews
  - Transcription
  - Small Scale (Ethics)
  - Small Scale (Data gath.)
  - Small Scale (Analysis)
  - Small Scale (Write up)
- **Case Conceptualisation**
  - Case Conceptualisation 1
  - Case Conceptualisation 2
- **Placement**
  - Placement 1
  - Placement 2
  - Placement 3
  - Placement 4
- **CC**
  - Small Scale (Ethics) Final
- **Teaching**
  - Viva
- **Write Up**
  - Write up (Methodology)
  - Write up (Introduction)
  - Write up (Discussion)
  - Write up (Write up)
- **Holiday Time**
  - 1
  - 2
  - 2
  - 1

### Notes:
- Outline a timetable for completion of key stages of the project (e.g., ethics submission, start and end of data collection, data analysis, completion of systematic review).
- Holiday time can be spread out over the three years.
Management of Risks to Project

11) Please summarise the main potential risks to your study, the perceived likelihood of occurrence of these risks and any steps you will or have taken to reduce these risks. Outline how you will respond to identified risks if they should occur.

During the interview there is a risk that participants may inadvertently divulge information that could allow for identification of their clients. While this is unlikely, as clinical psychologists regularly have to manage the boundaries of confidentiality in complex settings, should it happen, all identifying information will not be transcribed and remain only in the original audio recording, which will be securely destroyed following data analysis.

There is a risk that participants could divulge information that causes concern over their fitness to practice, or to the safety of a child or vulnerable adult. By selecting only participants who are registered with the HCPC or equivalent, this risk is minimised through requirements for registration and on-going training. However, should this occur, the researcher will discuss this issue with both clinical and academic supervisors. If it felt that there might be a risk to patients, the researcher’s supervisors will make contact with the participant for further clarification. If there are remaining concerns, the participant’s line manager, or the HCPC (if the participant is practicing independently), will be contacted in the case of concerns over fitness to practice. If these concerns are with regard to children or vulnerable adults, and supervisors do not feel that risks are being adequately managed, they will make contact with the relevant Social Work department to raise their concerns. Participants will be made aware of this process through information provided prior to consent. It will be reiterated at the start of each interview.

Knowledge Exchange

12) How do you intend to report and disseminate the results of the study? (IRAS A51)

The results of this study will be published as part fulfilment of the researcher’s thesis for the Doctorate in Clinical Psychology at the University of Edinburgh. Additionally, the results of this study will be submitted to peer-reviewed journals for consideration for publication. All participants will be offered electronic copies of the research report. Finally, the researcher is a
lecturer and writer within the field of Autism Spectrum Disorders, and the findings of this study will be incorporated into these presentations and publications.

13) What are the anticipated benefits or implications for services of the project? (E.g. If this is an NHS based project, in what way(s) is the project intended to benefit the NHS?)

Within the NHS, it is hoped that the results of this study will provide a basis for guidance for clinicians on how to diagnose girls with Autism Spectrum Disorders. In particular, this guidance would address common concerns/problems in diagnosing girls with ASD, educate on how girls may present differently, and provide guidance on how the diagnostic criteria can be interpreted for the diagnosis of girls on the spectrum. It is anticipated that the process of reflecting on their clinical experience, and questions around diagnostic issues in ASD will be beneficial for clinicians and improve their confidence and understanding of ASD. More broadly, it is anticipated that improved understanding of girls on the spectrum may lead to earlier recognition and more accurate diagnosis. This research may also benefit other research into ASDs by defining if and how girls with ASDs present, which could allow researchers to minimise the gender bias within their studies.

14) Are there any potential costs to this project?
Outline any potential financial costs to the project, including the justification for the costs (why are these necessary for the research project?) and how funding will be obtained for these costs (how will cost be met?). Please separate these into potential costs for the University and potential costs for your NHS Health board and note that you should ask your NHS Health board to meet stationery, printing, postage and travel costs.

A Dictaphone will be required to record interviews. Several Dictaphones are already owned by NHS Fife and the University of Edinburgh, and as such should not represent an expense.

While it is possible to do interviews over Skype, participants may prefer to conduct interviews in person. Where this is preferred, travel to major UK cities may be required, although overnight accommodation would hopefully be avoided. The expected cost of this would be no more than £250, and would be a travel expense to be met by the University of Edinburgh.
The researcher intends to use the online programme Dedoose for the analysis. This has a cost of $10.95 per month, for up to two years (allowing time for the author to familiarise himself with the programme, and for any additional analysis to be conducted for publication after the submission of the thesis). This has a projected cost of (including discount for annual payment) £150, to be met by the Researcher.

15) Any other relevant information.

16) Key References


Radua, E., Cardoner, N., Happe, F., Mataix-Cols, D (2011). Meta-analysis of grey matter abnormalities in autism spectrum disorder; should Asperger disorder be subsumed under a broader umbrella of autistic spectrum disorder? *Archives of General Psychiatry* 68. 409-418


Appendix 1:
Methodological Review

Main Academic Thesis Supervisor’s Appraisal of Project Risk

Supervisor’s Name: Ken MacMahon

Do you consider that the project should proceed in broadly its current form?
(Delete as appropriate)

Yes Subject to revisions outlined below No

Please outline the reasons for your response. In particular, highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks:

I believe that this project examines an area that is of theoretical interest, as well as of significant importance in clinical practice. Hence, this study would be a valuable addition to the literature.

With regard to risk, the most substantial would appear to be difficulties recruiting a sufficient number of clinicians with the degree of experience required. In particular, if the gender ratio of assessment queries favours boys substantially over girls, then clinicians will see far fewer girls than boys. However, preliminary assessment of interest amongst clinicians suggests that this is an area that is of interest to them (which would increase the probability of participation) and there are services that conduct substantial numbers of assessments. The researcher also has contacts with a number of clinicians within the field, which will be of benefit.

The use of Skype to conduct some interviews (if it is felt necessary, or desirable for the project, to go further afield) may present some risks if there are differences in data quality. However, as noted within the proposal, this method has been used, successfully, previously. A comparison of data gathered face-to-face and by Skype would be a means of establishing comparability.

Date: 12th July 2015
Appendix 2:
Methodological Review

Clinical Thesis Supervisor’s Appraisal of Project Risk

Supervisor’s Name: Katrina Johnston

Position: Clinical Psychologist

Do you consider that the project should proceed in broadly its current form?
(Delete as appropriate)

Yes  Yes, subject to revisions outlined below  No

Please outline the reasons for your response. In particular, highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks:
Doctorate Research Agreement

Supervisor and Trainee Responsibilities: Research Agreement

(This research agreement is provided as a sample only and supervisors / trainees may use any variations that are mutually agreed)

Trainee / Student name:

Joshua Muggleton

Title of Research Project:

A qualitative study of highly experienced clinical psychologist and their process for diagnosing girls on the autism spectrum.
Academic Supervisor(s):

Name: Ken MacMahon  
Position: Senior Lecturer in Clinical Psychology  
Affiliation: Clinical and Health Psychology, University of Edinburgh

Clinical Supervisor:

Name: Katrina Johnston  
Position: Clinical Psychologist  
Affiliation: NHS Fife

Responsibilities/expectations:

(1) Student / Trainee:

(a) To conduct suitable literature searches and prepare a well grounded proposal for research which could contribute to clinical practice and/or knowledge.

(b) To obtain suitable ethical approval for the study (& other approval where applicable).

(c) To adhere to relevant university regulations for the preparation and submission of theses.

(d) To have responsibility and ownership of all data collection and data analysis, to manage personal data appropriately, to adhere to research governance guidance regarding storage and archiving of unidentifiable research data and to prepare chapters for the thesis.

(e) To submit draft chapters to supervisors on agreed dates.

(f) To make amendments to the thesis in accordance with comments from examiners and university regulations.

(g) To disseminate findings appropriately in consultation with supervisors / other collaborators. Where appropriate, supervisors should be recognised as co-authors in any journal or conference papers or other outputs (see Handbook Section R.5).

(h) To keep supervisors regularly informed of progress, and arrange supervision.

(2) Academic Supervisor(s):

(a) To provide advice / comments upon proposals, study design, ethics applications, research data archiving and other aspects of the thesis project and small scale project.
(b) To meet, where possible, once every two months for supervision, or as mutually agreed as required.

(c) To read a draft version of each proposal or chapter and provide detailed comments within four weeks of receipt (where drafts are received on mutually agreed dates).

(d) To read and comment upon a second version of each chapter, either individually or as part of the full draft of the thesis received at least one month prior to the submission date.

(e) To provide advice on any amendments required subsequent to viva.

(f) To facilitate dissemination of findings where applicable and comment upon manuscripts submitted for publication.

(g) To assist, where possible, with the recruitment of participants

(3) Clinical Supervisor / Research Collaborator*: (where applicable)

(a) To provide advice / comments upon proposals, study design & ethics applications for the thesis project and small scale project.

(b) To meet, where possible, once every month for supervision, or as mutually agreed as required.

(c) To assist, where possible, with recruitment of participants

(d) By arrangement, to read and comment upon draft chapters

(e) To facilitate dissemination of findings where applicable and comment upon manuscripts submitted for publication.

(f) To provide triangulation for extracts of transcripts and themes

Other Responsibilities: (add any additional responsibilities)

Please note that it is not the role of supervisor(s) to proof read chapters. The onus is on students / trainees to ensure that proposals and chapters are well written.

Ethical Knowledge Exchange

There is an ethical responsibility to appropriately disseminate research findings where these would contribute to clinical practice and / or understanding. Studies usually involve notable investments of time and other resources from health care professionals, supervisors, and patients – most of whom participate on the understanding that the findings might benefit others. Naturally findings can only be of benefit to others if the results are appropriately disseminated via presentations and / or publication.

Dissemination may take many forms, such as the presentation of results to local health care professionals, patient groups or other interested parties; talks or posters at relevant meetings or conferences; or more widely via publication as journal articles. The trainee, all supervisors and any other relevant collaborators* should be recognised as authors in any publications or other outputs (e.g. posters / presentations) derived from the project where their involvement would meet criteria for authorship.
Preferably, the student / trainee should be first author and should prepare the manuscript, receiving suitable advice, assistance and encouragement from supervisors and other collaborators as relevant. All such publications / presentations should be circulated to all authors for comment prior to being submitted / presented.

It is suggested that if the student / trainee is unable to prepare work to a standard suitable for submission to relevant conference(s) or journal(s) within one year of completing the project (or another agreed time-frame), then with the agreement of the student / trainee and the other authors the academic supervisor may endeavour to prepare and submit findings that would make a reasonable contribution to the literature. In these circumstances, particularly if substantial rewriting is required, the academic supervisor may become the first author and the student / trainee would be an author on the paper.

It is recommended that supervisors and students / trainees discuss dissemination and agree respective roles / expectations regarding dissemination of results early in the supervision process. This conversation should involve all others contributing to the project and aim to reach a clear agreement about authorship or acknowledgment.

*: Note that the term collaborator is used here to refer to someone who has given substantial intellectual contribution to the project which would warrant recognition as co-author in relevant outputs. Others might contribute to the project in other ways which might be more appropriately recognised as an acknowledgement.

Confirmation of agreement (completed by trainee)

I confirm that each of the following have agreed this version of the research agreement and have agreed to meet the above responsibilities and expectations:

<table>
<thead>
<tr>
<th>Name(s)</th>
<th>Agree with above statement</th>
<th>Date</th>
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<tr>
<td>Trainee / student:</td>
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<td>Academic supervisor(s)</td>
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<td>Clinical Supervisor(s)</td>
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<tr>
<td>Research collaborator(s) (if any)</td>
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(All parties should be sent a copy of the final version of this agreement by the trainee)
Appendix 2O: Submission for ethical approval to the University of Edinburgh

Appendix 2O is presented on the following 12 pages
The forms required when seeking ethical approval in the School of Health and Social Sciences have now been merged into this single electronic document. The sections you are required to complete will depend on the nature of your application. Please start to complete the form from the beginning and proceed as guided. On completion the entire document should be submitted electronically to your section’s ethics tutor using the email addresses detailed on the final page.

### FORM OVERVIEW

<table>
<thead>
<tr>
<th>FORM</th>
<th>COMPLETION</th>
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<tbody>
<tr>
<td>Project registration form</td>
<td>: Compulsory for all applications</td>
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<tr>
<td>Document checklist</td>
<td>: Compulsory for all applications</td>
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<tr>
<td>Level 1 Self Audit form</td>
<td>: To be completed for all research studies that are not subject to review by an external UK based ethical committee.</td>
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<tr>
<td>Level 2 /3 ethical review form</td>
<td>: To be completed when indicated by responses on the Level 1 form.</td>
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### PROJECT REGISTRATION FORM

This form is the first stage in applying for University ethical approval and should be completed prior to the commencement of any research project. Applications submitted without appropriate documentation will be returned.

Ethical approval is required for all projects by staff or students conducting research, or similar. Applicants should familiarise themselves with the School’s Research Ethics Policy prior to completion.

<table>
<thead>
<tr>
<th>PR1 Name of Applicant:</th>
<th>Joshua Muggleton</th>
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<tr>
<td>PR2 Name of Supervisor¹:</td>
<td>Ken MacMahon</td>
</tr>
<tr>
<td>PR3 Project Title:</td>
<td>A qualitative study of highly experienced clinical psychologists’ conceptions of autism and gender differences in presentation and diagnosis</td>
</tr>
<tr>
<td>PR4 Subject Area (section of school):</td>
<td>Clinical Psychology</td>
</tr>
<tr>
<td>PR5 If student, type of assessed work that this application relates to:</td>
<td>Doctoral Level thesis</td>
</tr>
<tr>
<td>PR6 Planned date of project submission:</td>
<td>May 2017</td>
</tr>
<tr>
<td>PR7 Date ethics application submitted:</td>
<td>8th September 2015</td>
</tr>
<tr>
<td>PR8 Date complete information submitted if different):</td>
<td></td>
</tr>
<tr>
<td>PR9 IRAS Approval Number if applicable:</td>
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</table>

The following to be completed by ethics administrator

| PR10 Date of initial response to applicant: | |
| PR11 Date of final approval: | |
| PR12 Amendments Requested Date: | |
| PR13 Amendments Approved Date: | |
| PR14 Reviewer 1 | |
| PR15 Reviewer 2 | Level 2-3 only |

¹ Not applicable to staff members.
1) **DC1** Does your research project require extraction or collection of data abroad? (✔)

- **No** If ‘No’ Skip to Q2
- **Yes** Local Ethical review needed, please confirm (✔) electronic attachment of:
  - Application to ethical review panel in country of data collection (in English) + copy of letter of approval

2) **DC2** For the purposes of this research study, will you access identifiable\(^2\) information on any NHS patient? (✔)

- **No** If ‘No’ Skip to Q3
- **Yes** Please confirm (✔) electronic attachment of:
  - Caldicott Guardian approval for use of NHS data (or confirmation that it is not required)

3) **DC3** Does the project require ethical review by an external UK committee e.g. NHS REC or Social Work?

- **No** If ‘No’ Skip to Q4
- **Yes** Please confirm (✔) electronic attachment of:
  - NHS REC (IRAS) /other application form + copy of letter of approval

**NOTE:** You are not required to complete University ethical review forms. Skip to Q6

4) **DC4** Unless you answered ‘yes’ to 3, you must also obtain ethical approval through the University of Edinburgh process. Please submit a Level 1 form (with ‘Methods’ summary) and, if indicated, a level 2-3 form as well.

   SHSS Ethics paperwork

<table>
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<tr>
<th>Forms: level 1</th>
<th>Summary of 'Methods'</th>
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   Please indicate the SHSS Ethics forms completed herewith (✔):

5) **DC5** If you have completed the Level 2/3 form please list any additional documentation provided in support of your application (E.g. Disclosure, consent form, participant information, GP letters etc.)

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<tr>
<th>Documentation Name</th>
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<tr>
<td>Participant information sheet and consent form (Version 3)</td>
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<tr>
<td>Letter from East of Scotland Research Ethics Service</td>
<td>✔️</td>
<td></td>
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<tr>
<td>Interview Schedule (Version 6)</td>
<td>✔️</td>
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6) **Signatures**

   _Joshua Muggleton_ ___________________________  _08/09/2015_
   Applicant’s Name  Applicant’s Signature  Date signed

   _Kenneth MacMahon_ ___________________________  _04/09/2015_
   Supervisor’s Name  Supervisor’s Signature  Date signed

---

\(^2\) ‘Identifiable information’ refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients’ names.

\(^3\) Not required for staff applications.
Please return an electronic copy of your UoE HSS Ethics Application Form (in its entirety) to your Section’s Ethics Tutor, accompanied by electronic copies of additional documents indicated above. We do not accept paper documentation, please scan all documents into electronic formats. Please keep a copy of all documentation for your records.

LEVEL 1 SELF AUDIT FORM

The audit is to be conducted by all staff and students conducting any type of empirical investigation, including research, audit or service evaluation.

The form should be completed by the principal investigator and, with the exception of staff, signed by a University supervisor.

Primary Research Question:

Please tick

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<th>Please tick</th>
<th>What type of research are you planning to do?</th>
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<tr>
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<td>Study of a novel intervention or randomised clinical trial to compare interventions in clinical practice</td>
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<tr>
<td>✓</td>
<td>Study utilising questionnaires, interviews or measures, including auto-ethnographic.</td>
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<td></td>
<td>Study limited to working with routinely collected clinical data</td>
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<tr>
<td></td>
<td>Meta-analysis or systematic review</td>
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<tr>
<td></td>
<td>Research database containing non-identifiable information</td>
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</tbody>
</table>

Please provide a brief summary of your proposed study. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

Project Summary:

This project will interview highly experienced clinical psychologists to identify how they conceptualise Autism Spectrum Disorders (ASDs), and the gender differences within this group.

E-mails will be sent to heads of services that provide diagnostic assessments of ASD in children. Information regarding the study will be given, and a request to recruit clinicians from their services will be made. If this is granted, contact will be made with individual clinicians, providing them with information about the project, and asking if they would be willing to be placed on a list of prospective participants to be contacted in the future to take part. Services with clinicians that might meet inclusion criteria will be identified through personal contacts, public databases of ASD diagnostic services, research publications, and heads of service. The researcher and supervisors will then discuss the relative experience, perspectives and merits of all prospective participants, and select the 14 participants likely to provide the greatest depth and variety of experience.

Participants will be contacted via e-mail and asked if they would still like to take part in the study, and provided with further information on the study and the types of questions they may be asked. If they consent, they will be asked to attend an interview at a time and place convenient to them. This will primarily be done in person, but may be done via Skype if required. Participants will be interviewed using a semi-structured interview by the lead researcher. Before interviews start, participants will be asked if they have any further questions and to reiterate their verbal consent, in addition to their already obtained written consent. Participants will also be asked to refrain from disclosing identifying information about their clients. Participants will be free to pause or end the interview at any time. Interviews will last approximately 60-90 minutes.

Interviews will be audio recorded using a digital Dictaphone (when interviews are conducted in person), or using recording software (if conducted via Skype). The Dictaphone will be kept on the researcher’s person (in a locked bag) or in a locked drawer, within a locked office, in either NHS or University of Edinburgh premises at all times. Skype recordings will be backed up onto an external USB drive and kept in a locked drawer, with the original data recording will be deleted from the researcher’s laptop. Transport of materials will be via a locked bag.
Recordings will be transcribed onto a Microsoft Word Document by the interviewer. During transcription, any identifying information (such as, but not limited to, names), will be redacted or replaced with pseudonyms. Identifying information will therefore only exist in the original recording.

During the interview there is a risk that participants may inadvertently divulge information that could allow for identification of their clients. While this is unlikely, as clinical psychologists regularly have to manage the boundaries of confidentiality in complex settings, should it happen, all identifying information will not be transcribed and remain only in the original audio recording, which will be securely destroyed following data analysis.

There is a risk that participants could divulge information that causes concern over their fitness to practice, or to the safety of a child or vulnerable adult. By selecting only participants who are registered with the HCPC or equivalent, this risk is minimised through requirements for registration and on-going training. However, should this occur, the researcher will discuss this issue with both clinical and academic supervisors. If it felt that there might be a risk to patients, the researcher’s supervisors will make contact with the participant for further clarification. If there are remaining concerns, the participant’s line manager, or the HCPC (if the participant is practicing independently), will be contacted in the case of concerns over fitness to practice. If these concerns are with regard to children or vulnerable adults, and supervisors do not feel that risks are being adequately managed, they will make contact with the relevant Social Work department to raise their concerns. Participants will be made aware of this process through information provided prior to consent. It will be reiterated at the start of each interview.

Due to the nature of qualitative research, once analysis has begun on a transcript it is often not possible to extract the data from the analysis. Therefore, participants will have up to one week after the date of the interview to withdraw their data from the study, after which the researcher may begin transcription and analysis, and withdrawal of their data may no longer be possible. Should a participant wish to withdraw their data once data analysis has begun, every effort will be made to follow this request, but analysed data may not be extractable. Participants will be fully informed of this. Only participants’ consent forms will record who has taken part in the interview, and will not link names to pseudonyms. These will be kept in a separate locked drawer, in a locked office, in either NHS or University of Edinburgh premises.

Data will be analysed using thematic analysis. After analysis is complete, participants will be asked if they would like to review the analysis and comment on its validity and accuracy.

The transcripts will be securely held in the University of Edinburgh Data Repository for 10 years.

Please circle your answer as appropriate:

<table>
<thead>
<tr>
<th>ETHICAL ISSUES</th>
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<tbody>
<tr>
<td><strong>SA 3</strong></td>
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<tr>
<td><strong>Bringing the University into disrepute</strong></td>
<td><strong>No</strong></td>
<td><strong>Yes</strong></td>
</tr>
<tr>
<td>Is there any aspect of the proposed research which might bring the University into disrepute? For example, could any aspect of the research be considered controversial or prejudiced?</td>
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<tr>
<td><strong>SA 4</strong></td>
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<tr>
<td><strong>Protection of research subject confidentiality</strong></td>
<td><strong>No</strong></td>
<td><strong>Yes</strong></td>
</tr>
<tr>
<td><em>Will you make every effort to protect research subject confidentiality by conforming to the University of Edinburgh’s guidance on data security, protection and confidentiality as specified in: <a href="http://www.ed.ac.uk/schools-departments/information-services/services/research-support/data-library/research-data-mgmt/data-security">http://www.ed.ac.uk/schools-departments/information-services/services/research-support/data-library/research-data-mgmt/data-security</a></em></td>
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<tr>
<td><em>For example, there are mutually understood agreements about:</em></td>
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<tr>
<td>(a) non-attribution of individual responses;</td>
<td></td>
<td></td>
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<tr>
<td>(b) Individuals, and organisations where necessary, being anonymised in stored data, publications and presentations;</td>
<td></td>
<td></td>
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<tr>
<td>(c) publication and feedback to participants and collaborators;</td>
<td></td>
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<tr>
<td>(d) With respect to auto-ethnographic work it is recognised that the subject’s anonymity cannot be maintained but the confidentiality of significant others must be addressed.</td>
<td></td>
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</tbody>
</table>
**Data protection and consent**

*Will you make every effort to ensure the confidentiality of any data arising from the project by complying with the University of Edinburgh’s Data Protection procedures (see [www.recordsmanagement.ed.ac.uk](http://www.recordsmanagement.ed.ac.uk))*;

For example

(a) Ensuring any participants recruited give consent regarding data collection, storage, archiving and destruction as appropriate;

(c) Identifying information⁴, (e.g. consent forms) is held separately from data and is only accessible by the chief investigator and their supervisors;

(e) There are no other special issues arising regarding confidentiality/consent.

(f) That where NHS data is being accessed Caldicott Guardian approval has been obtained.

**Duty to disseminate research findings**

Are there issues which will prevent all participants and relevant stakeholders having access to a clear, understandable and accurate summary of the research findings should they wish?

**Moral issues and Researcher/Institutional Conflicts of Interest**

*Are there any SPECIAL MORAL ISSUES/CONFLICTS OF INTEREST?*

Examples include, but are not limited to:

(a) Where the purposes of research are concealed;

(b) Where respondents are unable to provide informed consent

(c) Where there is financial or non-financial benefit for anyone involved in the research, or for their relative or friend.

(d) Where research findings could impinge negatively or differentially upon participants or stakeholders (for example when selecting an unrepresentative sample of a larger population).

(e) Where there is a dual relationship between the researcher and subject? E.g. Where the researcher is also the subject’s practitioner or clinician.

**Potential physical or psychological harm, discomfort or stress**

Is there any foreseeable potential for:

(a) significant psychological harm or stress for participants

(b) significant physical harm or discomfort for participants?

(c) significant risk to the researcher?

Examples of issues/topics that have the potential to cause psychological harm, discomfort or distress and should lead you to answer ‘yes’ to this question include, but are not limited to:

*Relationship breakdown; bullying; bereavement; mental health difficulties; trauma / PTSD; Violence or sexual violence; physical, sexual or emotional abuse in either children or adults; feedback of results from the project’s assessments.*

---

⁴ ‘Identifiable information’ refers to information that would allow you to know, or be able to deduce, the identity of a patient. The most common examples of this would be accessing medical records or similar, or accessing a database that includes patients’ names.
Assessment outcome:

**SA10** Have you circled any answers in BOLD typescript? Please tick as appropriate

**No**

(i) Your responses on the completed self-audit confirm the ABSENCE OF REASONABLY FORESEEABLE ETHICAL RISKS.

(ii) Please now read the guidance below and provide the required signatures.

(iii) You are NOT REQUIRED to complete a level 2/3 application form.

(iv) Please submit the UoE HSS Ethics Application Form electronic document (in its entirety) along with ALL additional required documentation, failure to do so will mean that your form is returned to you.

**Yes**

(i) Your responses on the completed self-audit indicate that we require further information to consider your application.

(ii) Read the Guidance below and provide the required signatures.

(iii) You ARE REQUIRED to complete a level 2/3 application form.

(iv) Please continue to page x of this document where you will find the level 2/3 form

---

**Vulnerable participants**

Will you be recruiting any participants or interviewees who could be considered vulnerable?

Examples of vulnerable groups, the inclusion of which should lead you to answer yes to this question include, but are not limited to:

- Clients or patients of either the researcher OR the person recruiting subjects; Children & young people; people who are in custody or care for example, offenders, looked after children or nursing home resident; persons with mental health difficulties including those accessing self-help groups; auto-ethnographic researchers examining distressing topics.

---

**Subsequent to submission of this form, any alterations in the proposed methodology of the project should be reviewed by both the applicant and their supervisor. If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is required.**

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

---

ALL forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

_____________________
Applicant’s Name
_____________________
Applicant’s Signature
_____________________
Date

_____________________
Supervisor Name
_____________________
Date

*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all ‘No’ answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

---

*Not required for staff applications
LEVEL 2 / 3 ETHICAL REVIEW

- Complete only if indicated in the conclusion of your level 1 form.
- Applications will be monitored and audited to ensure that the School Ethics Policy and Procedures are being complied with and applicants contacted in cases where there may be particular concerns or queries.
- Research must not proceed before ethical approval has been granted. For this reason it is particularly important that applications are submitted well in advance of any required date of approval.

If the answer to any of the questions below is ‘yes’, please elaborate and give details of how this issue is will be addressed to ensure that ethical standards are maintained. The response boxes will expand as you complete them. Forms that do not contain sufficient detail will be returned incurring delay.

### RISKS TO, AND SAFETY OF, RESEARCHERS NAMED IN THIS APPLICATION

<table>
<thead>
<tr>
<th>ER1 Do any of those conducting the research named above need appropriate training to enable them to conduct the proposed research safely and in accordance with the ethical principles set out by the College?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>YES / NO</strong></td>
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<table>
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<tr>
<th>ER2 Are any of the researchers likely to be sent or go to any areas where their safety may be compromised, or they may need support to deal with difficult issues?</th>
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<tbody>
<tr>
<td><strong>YES / NO</strong></td>
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<table>
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<tr>
<th>ER3 Could researchers have any conflicts of interest?</th>
</tr>
</thead>
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<tr>
<td><strong>YES / NO</strong></td>
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</tbody>
</table>

### RISKS TO, AND SAFETY OF, PARTICIPANTS

<table>
<thead>
<tr>
<th>ER4 Are any of your participants children or protected adults (protected adults are those in receipt of registered care, health, community care or welfare services – please refer to <a href="http://www.disclosurescotland.co.uk/guidance/infoforindivid/chap2_regulatedwork/2_3_step_2_define.html">http://www.disclosurescotland.co.uk/guidance/infoforindivid/chap2_regulatedwork/2_3_step_2_define.html</a>)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anyone who will have contact with children or protected adults requires approval from Disclosure Scotland at <a href="http://www.disclosurescotland.co.uk/">http://www.disclosurescotland.co.uk/</a></td>
</tr>
</tbody>
</table>

Do any of the researchers taking part in this study require Disclosure Scotland approval? (V)

<table>
<thead>
<tr>
<th>Not applicable</th>
<th>Relevant researcher/s has current Disclosure Scotland approval through a current NHS employment contract</th>
<th>Yes*</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Ethical approval will be subject to documentation confirming Disclosure Scotland approval with this form.</td>
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</table>
**Could the research induce any psychological stress or discomfort?**

**YES / NO**

There is a risk that participants could divulge information that causes concern over their fitness to practice, or to the safety of a child or vulnerable adult. By selecting only participants who are registered with the HCPC or equivalent, this risk is minimised through requirements for registration and on-going training. However, should this occur, the researcher will discuss this issue with both clinical and academic supervisors. If it felt that there might be a risk to patients, the researcher’s supervisors will make contact with the participant for further clarification. If there are remaining concerns, the participant’s line manager, or the HCPC (if the participant is practicing independently), will be contacted in the case of concerns over fitness to practice. If these concerns are with regard to children or vulnerable adults, and supervisors do not feel that risks are being adequately managed, they will make contact with the relevant Social Work department to raise their concerns. Either of these scenarios may cause the participant significant distress. However, participants will be made aware of this process through information provided prior to consent. It will be reiterated at the start of each interview.

**Does the research involve any physically invasive or potentially physically harmful procedures?**

**YES / NO**

**Could this research adversely affect participants in any other way?**

**YES / NO**

**RESEARCH DESIGN**

**Does the research involves living human subjects specifically recruited for this research project**

*If ‘no’, go to section 6*

**YES / NO**

Participants will be recruited using non-probabilistic, purposive sampling. This will allow for the creation of a sample with significant and broad experience of autism in children. To this end, researchers will target highly experienced clinical psychologists, who have diagnosed many cases of ASD in both males and females. Participant recruitment will focus on clinical psychologists working for the NHS in the UK, but may include clinical psychologists in other settings.

**How many participants will be involved in the study?**

14
**What criteria will be used in deciding on inclusion/exclusion of participants?**

**Inclusion criteria**

1. Qualified Clinical Psychologist registered with the HCPC or their national equivalent
2. Have substantive experience in diagnosing children (<18 years) with ASDs.

Note: “Substantive experience” is a deliberately broad term, which relies largely on the personal self-evaluation of prospective participants, and the researcher’s opinion. This was chosen deliberately as quantifying a number of diagnostic cases may not necessarily yield a high degree of experience. For example, working with a comparatively small number of very complex/borderline cases may give more information than administering a screening questionnaire to a large number of relatively straightforward diagnostic cases.

Note: It was decided to limit analysis to examples of diagnosing those under 18. It was felt that child and adult presentations would be qualitatively different, and increase the heterogeneity of the data. Given that people are most frequently diagnosed in childhood, and that early accurate diagnosis allows for earlier supportive interventions, it was decided to focus on child presentations only. While participants may have worked with, or be actively working with, adults with ASD, they must have significant experience with under 18s with ASD to draw upon, as examples given during interviews based on adult presentations will be excluded from the analysis.

**Exclusion criteria**

1. Experience is based predominantly with adults with ASD
2. Experience is based predominantly on people with ASD and a comorbid Learning Disability
3. Limited experience diagnosing or working with girls with ASD
4. A high number of colleagues from the same service also taking part in the study

**How will the sample be recruited? (E.g. posters, letters, a direct approach- specify by whom.)**

E-mails will be sent to heads of services that provide diagnostic assessments of ASD in children. Information regarding the study will be given, and a request to recruit clinicians from their services will be made. If this is granted, contact will be made with individual clinicians, providing them with information about the project, and asking if they would be willing to be placed on a list of prospective participants to be contacted in the future to take part. Services with clinicians that might meet inclusion criteria will be identified through personal contacts, public databases of ASD diagnostic services, research publications, and heads of service. The researcher and supervisors will then discuss the relative experience, perspectives and merits of all prospective participants, and select the 14 participants likely to provide the greatest depth and variety of experience.

Participants will be contacted via e-mail and asked if they would still like to take part in the study, and provided with further information on the study and the types of questions they may be asked.

**Will the study involve groups or individuals who are in custody or care, such as students at school, self-help groups, residents of nursing home?**

**YES / NO**

**Will there be a control group?**

**YES / NO**

**What information will be provided to participants prior to their consent? (e.g. information leaflet, briefing session)**

**YES / NO**
Participants will be provided with an information sheet, and the opportunity to ask questions to the researcher in person, or via e-mail.

**ER15** Participants have a right to withdraw from the study at any time. Please tick to confirm that participants will be advised of their rights, including the right to continue receiving services if they withdraw from the study.

Yes, participants will be advised of their rights. However, as outlined above, due to the nature of qualitative research, once analysis has begun on a transcript it is often not possible to extract the data from the analysis. Therefore, participants will have up to one week after the date of the interview to withdraw their data from the study, after which the researcher may begin transcription and analysis, and withdrawal of their data may no longer be possible, although every effort will be made to do so. Participants will be fully informed of this.

**ER16** Will it be necessary for participants to take part in the study without their knowledge and consent? (e.g. covert observation of people in non-public places)

**YES / NO**

Where consent is obtained, what steps will be taken to ensure that a written record is maintained?

Written consent forms will be retained, in a secure manner, for the duration of the study.

**ER18** In the case of participants whose first language is not English, what arrangements are being made to ensure informed consent?

As a requirement for training and practice in Clinical Psychology in the UK, all participants will be proficient in English.

**ER19** Will participants receive any financial or other benefit from their participation?

**YES / NO**

**ER20** Are any of the participants likely to be particularly vulnerable, such as elderly or disabled people, adults with incapacity, your own students, members of ethnic minorities, or in a professional or client relationship with the researcher?

**YES / NO**

Up to two participants may be recruited from the same psychology department as the researcher. However, like all participants, they would not be directly recruited by the researcher, minimising any feelings of obligation to participate.

**ER21** Will any of the participants be under 16 years of age?

**YES / NO**

**ER22** Will any of the participants be interviewed in situations which will compromise their ability to give informed consent, such as in prison, residential care, or the care of the local authority?
**DATA PROTECTION**

<table>
<thead>
<tr>
<th>ER23</th>
<th>Will any part of the research involve audio, film or video recording of individuals?</th>
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<tbody>
<tr>
<td><strong>YES / NO</strong></td>
<td>Interviews will be audio recorded and transcribed verbatim by the researcher</td>
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<tr>
<th>ER24</th>
<th>Will the research require collection of personal information from any persons without their direct consent?</th>
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<tr>
<td><strong>YES / NO</strong></td>
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<tr>
<th>ER25</th>
<th>How will the confidentiality of data, including the identity of participants (whether specifically recruited for the research or not) be ensured?</th>
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Participants will not routinely need to use their name during interviews. They will be reminded not to reveal identifying details of their clients before the interview. If the researcher considers there has been a breach of a participant’s or client’s confidentiality (e.g. full name, location they work, etc), then researcher will redact that information during transcription. Transcripts will be given pseudonyms. There will be no key to relate a participant to a pseudonym.

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<tr>
<th>ER26</th>
<th>Who will be entitled to have access to the raw data?</th>
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Audio recordings will be accessed by the researcher for the purpose of transcription. The transcripts will be accessed by the researcher and supervisors for triangulation. After the study, the transcripts may be accessed by other researchers making a legitimate research-based request to use the data.

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<th>ER27</th>
<th>How and where will the data be stored, in what format, and for how long?</th>
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Short term, the data will be stored on an audio recording device (see below for security). As soon as is practical, the data will be transcribed onto a computer in word document format (see below for security). The data will then be stored on the computer for the duration of the study. After this, the data will be transferred to the University of Edinburgh for secure long-term storage for 10 years.

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<tr>
<th>ER28</th>
<th>What steps have been taken to ensure that only entitled persons will have access to the data?</th>
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The audio recording device will either be password protected, or stored and transported in a locked container. Once the files have been transferred to computer, the files will be deleted from the audio recording device. The computer will be password protected, and the files encrypted. The computer will be stored behind at least 1 locked door when not on the CIs person. The computer, audio recording device and any other data will be stored in a locked bag when being transported.

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<tr>
<th>ER29</th>
<th>How will the data be disposed of?</th>
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The data will be deleted from the audio recording device, and from the computer in accordance with University of Edinburgh guidance on secure deletion of data.

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<tr>
<th>ER30</th>
<th>How will the results of the research be used?</th>
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</table>
The results of this study will be published as part fulfilment of the researcher’s thesis for the Doctorate in Clinical Psychology at the University of Edinburgh. Additionally, the results of this study will be submitted to peer-reviewed journals for consideration for publication. All participants will be offered electronic copies of the research report. Finally, the researcher is a lecturer and writer within the field of Autism Spectrum Disorders, and the findings of this study will be incorporated into these presentations and publications.

**ER31 What feedback of findings will be given to participants?**

Participants will be asked if they would like to receive a copy of the analysis before write up to read and comment on, in order to ensure the validity of the analysis. After write up, participants will be sent a final copy of the report.

**ER32 Is any information likely to be passed on to external companies or organisations in the course of the research?**

**YES / NO**

**ER33 Will the project involve the transfer of personal data to countries outside the European Economic Area?**

**YES / NO**

**ER34** An application at this level is likely to require additional documentation, for example consent forms or participant information sheets. Please return to the Documentation Checklist on page 2 to list your supporting documentation.

---

**BRINGING THE UNIVERSITY INTO DISREPUTE**

If on the level one form you have answered ‘yes’ that some aspect of the proposed research “might bring the University into disrepute”, please elaborate alongside how this might arise, and what steps will be taken by the researcher to mitigate and / manage this, to minimise adverse consequences to the University.

---

**Subsequent to submission of this form, any alterations in the proposed methodology of the project should be reviewed by both the applicant and their supervisor. If the change to methodology results in a change to any answer on the form, then a resubmission to the Ethics subgroup is required.**

The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

All forms should be submitted in electronic format. Digital signatures or scanned in originals are acceptable. The applicant should keep a copy of all forms for inclusion in their thesis.

Joshua Muggleton  
Applicant’s Name  
Signature  
Date

Kenneth MacMahon  
Supervisor Name  
Signature  
Date

---

* Supervisor Signature

---

6 Not required for staff applications
*NOTE to Supervisor: Ethical review will be based only on the information contained in this form. If countersigning this check-list as truly warranting all ‘No’ answers, you are taking responsibility, on behalf of the HSS and UoE, that the research proposed truly poses no ethical risks.

<table>
<thead>
<tr>
<th>ISSUES ARISING FROM THE PROPOSAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can confirm that the above application has been reviewed by two independent reviewers. It is their opinion that:</td>
</tr>
<tr>
<td>a) Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,</td>
</tr>
<tr>
<td>OR</td>
</tr>
<tr>
<td>b) The ethical issues listed below arise or require clarification:</td>
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</tbody>
</table>

The applicant should respond to these comments in section 8 below.

Signature:
Position:
Date:

<table>
<thead>
<tr>
<th>APPLICANT’S RESPONSE (If required)</th>
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<tr>
<td>Signature:</td>
</tr>
<tr>
<td>Date:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CONCLUSION TO ETHICAL REVIEW (if required)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The applicant’s response to our request for further clarification or amendments has now satisfied the requirements for ethical practice and the application has therefore been approved.</td>
</tr>
</tbody>
</table>

Signature:
Position:
Date:

<table>
<thead>
<tr>
<th>AMENDMENT/S: REQUEST FOR APPROVAL</th>
</tr>
</thead>
<tbody>
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<td></td>
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</tbody>
</table>
Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal.

As part of the process of approving the study's sponsorship by the university, Jo-Anne has asked me to make some revisions to the consent and information form. In particular:

- The header now contains a short study title and version number
- The footer now contains the date of the form and sheet number
- Logos have been included for NHS Fife and the University of Edinburgh to the information sheet and consent form
- Participants are now asked to initial each point on the consent form, in addition to signing it.
- The first consent item specifies the version of the information sheet participants are to have read
- Participants are asked to consent to being audio recorded
- Participants are explicitly asked to agree to take part on the study
- Clarification is added over research audit
- Notes regarding numbers of copies for each party are added
- Information sheet has more explicit information on why the participants have been invited, and whether or not they have to take part
- The information sheet has information about the organisation of the study
- An external contact and research governance contact are provided for complaints.

Signature: Joshua Muggleton
Date: 27.11.15

<table>
<thead>
<tr>
<th>CONCLUSION TO ETHICAL REVIEW OF AMENDMENT</th>
</tr>
</thead>
</table>

I can confirm that the above amendment has been reviewed by two independent reviewers. It is their opinion that:

a. Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,

Signature: [Signature]
Position: Lecturer in Clinical Psychology, Ethics Tutor
Date: 01/12/15

Acronyms / Terms Used
NHS: National Health Service
SHSS: School of Health in Social Science
IRAS: Integrated Research Applications System
Section: The SHSS is divided into Sections or subject areas, these are; Nursing Studies, Clinical Psychology, Counselling and Psychotherapy and Interdisciplinary Social Sciences in Health
Appendix 2P: Ethical Approval letter from the University of Edinburgh

Appendix 2P presented on the following page
07 October 2015

Dear Joshua,

Application for Level 2/3 Approval

**Project Title:** A qualitative study of highly experienced Clinical Psychologists' conceptions of autism and gender differences in presentation and diagnosis

**Academic Supervisor:** Ken MacMahon

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 7th October 2015.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kirsty Gardner
Administrator
Clinical Psychology
Appendix 2Q: University of Edinburgh Sponsorship documentation

Below is a screenshot of IRAS documenting that Mrs Jo-Anne Robertson, representative of the University of Edinburgh, signed off as sponsor on the project on the 8th of January 2016

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<th>Signing User</th>
<th>Action</th>
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<td>Sponsor's representative</td>
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<td>Mrs Jo-Anne Robertson</td>
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<tr>
<td>Chief Investigator</td>
<td>Signed and valid</td>
<td>Mr Joshua Muggleton</td>
<td></td>
</tr>
<tr>
<td>Academic supervisor</td>
<td>Signed and valid</td>
<td>Dr Kenneth MacMahon</td>
<td></td>
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<tr>
<td>Academic supervisor</td>
<td>Signed and valid</td>
<td>Dr Katrina Johnston</td>
<td></td>
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</table>

Electronic Authorisations History

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<td>Sponsor's representative</td>
<td>Request for authorisation sent by Mr Joshua Muggleton to Mrs Jo-Anne Robertson</td>
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</table>
Appendix 2R: Health Board Research and Development Office approval letters

The Research and Development Office approval for Fife, Glasgow, Guys and St Thomas’, Highland, Lothian, Northumberland Tyne and Weir, and Tayside are presented over the following 12 pages
Dear Mr Muggleton

**Project Title: A qualitative description of Autism Spectrum Disorder in girls**

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

<table>
<thead>
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<th>Document</th>
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<td>University of Edinburgh ethical approval</td>
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<td>Information for Heads of Service</td>
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<tr>
<td>IRAS SSI Form</td>
<td>5.2.1</td>
<td>16 February 2016</td>
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The terms of the approval state that you are the Principal Investigator authorised to undertake this study within NHS Fife.

I note that review by an NHS Research Ethics Committee has not been necessary since the study involves NHS staff only.

The sponsors for this study are University of Edinburgh.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr A Wood, R&D Manager, R&D Department, Queen Margaret Hospital, Whitefield Rd, Dunfermline, KY12 OSU (Amanda.wood3@nhs.net) in 12 months time and subsequently at yearly intervals until the work is completed. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

All research activity must comply with the standards detailed in the Research Governance Framework for Health & Community Care.

---

NHS Fife was awarded the Carbon Trust Standard in February 2010 and is the first Scottish NHS Board to achieve this accolade.
(http://www.cso.scot.nhs.uk/publications/resgov/resgov.htm), health & safety regulations, data protection principles, other appropriate statutory legislation and in accordance with Good Clinical Practice (GCP).

Any amendments which may subsequently be made to the study should also be notified to Aileen Yell, Research Governance Officer (aileenyell@nhs.net), as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data.

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or local Principal Investigator at a research site may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office (aileenyell@nhs.net) should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely,

DR FRANCES ELLIOT
Medical Director
NHS Fife

Cc: Aileen Yell, Research Governance Officer, NHS Fife, Queen Margaret Hospital, Dunfermline
Dear Mr Muggleton,

Study Title: A qualitative study of highly experienced clinical psychologists’ conceptions of autism and gender differences in presentation and diagnosis.

Principal Investigator: Mr Joshua Muggleton

GG&C HB site: Community Health Partnerships

Sponsor: University of Edinburgh

R&D reference: GN16LD033

REC reference: N/A

Protocol no: 15 July 2015

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

Conditions of Approval

1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

2. For all studies the following information is required during their lifespan.
   a. Recruitment Numbers on a quarterly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.
Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Kayleigh Pender
Senior Research Administrator
GSTFT R&D approval for "A Qualitative Description of Autism Spectrum Disorder in Girls" R&D Ref. 185772

Marcinkowski Mariusz <Mariusz.Marcinkowski@gstt.nhs.uk>
Wed 20/04/2016 17:18

To: Oszivadjian Ann <Ann.Oszivadjian@gstt.nhs.uk>;
Cc: MUGGLETON, Joshua (NHS FIFE);

Dear Dr Oszivadjian,

| Study Title: A Qualitative Description of Autism Spectrum Disorder in Girls | R&D No: 185772 |

Thank you for submitting your Project Application to the R&D Department. The project has now been approved by the Trust and has been allocated the Trust R&D registration number 185772. The project has been registered on the Trust's research database.

Please quote the R&D registration number in any communications with the R&D Department regarding your project.

Conditions of Approval:

- The Principal investigator must notify R&D of the actual end date of the project.
- The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.
- The agreed protocol must be followed. R&D must be notified of any changes to the protocol prior to implementation.

In line with the Research Governance Framework, your project may be randomly selected for monitoring for compliance against the standards set out in the Framework. For information, the Trust's process for the monitoring of projects and the associated guidance is available from the Trust's intranet or on request from the R&D Department. You will be notified by the R&D Department if and when your project has been selected as part of the monitoring process. No action is needed until that time.

Many thanks for registering your project

Kind regards
Mariusz Marcinkowski
NIHR GSTFT/KCL Biomedical Research Centre
T: +44 (0)20 7188 7188 Ext: 53528 | F: 0207 188 8330 |
T: mariusz.marcinkowski@gstt.nhs.uk | W: www.guysandsthomas.nhs.uk/

Guy’s and St Thomas’ and King’s College London working together with our partners to deliver better health through research www.guysandsthomasbrc.nihr.ac.uk

The information contained in this message and or attachments is intended only for the person or entity to which it is addressed and may contain confidential and/or privileged material.

https://email.nhs.net/owa/#viewmodel=ReadMessageItem&itemId=AAAmkADkZWNZDY5LWRmMDAxNDUyNy1hNmJiLWRmMDk5Y2MyZjIzZgBGAAA… 1/1
06 April 2016

Mr Joshua Muggleton
Trainee Clinical Psychologist
NHS Fife
Lynnebank Hospital
Halbeath Road
Dunfermline
KY11 8JH

Dear Mr Muggleton,

**Management Approval for Non-Commercial Research**

I am pleased to tell you that you now have Management Approval for the research project entitled: 'A qualitative study of highly experienced clinical psychologists' conceptions of autism and gender differences in presentation and diagnosis'. [Protocol No Version 15/07/15]. I acknowledge that:

- The project is sponsored by the University of Edinburgh.
- The project does not require external funding.
- Research Ethics Committee approval is not required for the project as it involves staff only.
- The project is Site-Specific Assessment exempt.

The following conditions apply:

The responsibility for monitoring and auditing this project lies with the University of Edinburgh.

NHS Highland R&D ID: 1175
NRSPCC ID: NRS16/185772

Headquarters:
NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: Mr Garry Coutts
Chief Executive: Elaine Mead

*Highland NHS Board is the common name of Highland Health Board*
• This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.
• All amendments (minor or substantial) to the protocol should be submitted to the NHS Highland Research and Development Office to obtain amendment approval.
• The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant’s involvement in this project should be copied to the NHS Highland R&D Office.
• Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net).

Yours sincerely,

Frances Hines
R&D Manager

cc Frances Hines, R&D Manager, NHS Highland Research & Development Office,
Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH
University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

FM/MT/approval

25 January 2016

Mr Joshua Muggleton
NHS Fife
Lynedoch Hospital
Halbeath Road
Dunfermline
KY11 8JH

Research & Development
Room E1.12
Tel: 0131 242 3330
Email: RDOOffice@nhslothian.scot.nhs.uk
Director: Professor David E Newby

Dear Mr Muggleton

Lothian R&D Project No: 2016/0029

Title of Research: A qualitative study of highly experienced clinical psychologists conceptions of autism and gender differences in presentation and diagnosis.

REC No: N/A

Participant Information Sheet: Version 1 dated 08 September 2015
Consent Form: Version 1 dated 08 September 2015

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely,

Fiona Mc Ardle
Deputy R&D Director

cc. Tim Montgomery, Director of Operations, Royal Edinburgh & Associated Services
    Helen Griffiths, Consultant Clinical Psychologist, CAMHS
04/03/16

RES-16-008

Joshua Muggleton
Trainee Clinical Psychologist
University of Edinburgh

Dear Josh

Re: A qualitative study of highly experienced clinical psychologists’ conceptions of autism and gender differences in presentation and diagnosis

I write to confirm that Northumberland, Tyne and Wear NHS Foundation Trust are happy to support and approve the above study. Please accept this letter as verification of Trust approval.

Approval is granted with the condition that the R&D Department are notified of:

- Commencement and completion of the study
- Any significant changes to the study design
- Suspension or abandonment of the study
- All publications and/or conference presentation of the study findings

The Department of Health’s minimum standards for research governance state that at least 10% of projects should be routinely audited. It is a condition of our approval that the researchers accept the Trust’s right to include this project in the auditing and monitoring process.

Best wishes

Yours sincerely

Simon Douglas
Head of Research, Innovation and Clinical Effectiveness
25 April 2016

Mr Joshua Muggleton
NHS Fife
Lyncbank Hospital
Halbeath Road
Dunfermline
KY11 8JH

Dear Mr Muggleton,

R&D MANAGEMENT APPROVAL – TAYSIDE

Title: A qualitative study of highly experienced clinical psychologists’ conceptions of autism and gender differences in presentation and diagnosis.

Chief Investigator: Mr Joshua Muggleton

Principal Investigator/Local Collaborator: n/a

Tayside Ref: 2015PZ01 NRS Ref: NRS16/185772

R&D Ref: n/a

Sponsor: University of Edinburgh

Funder: no external funding

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).

- All amendments to be notified to TASC R&D Office via the correct amendment pathway. Either direct to the R&D Office or via the Lead Co-ordinating Centre depending on how the study is set up (http://www.hra.nhs.uk/nhsfasc-nd-uk-process-management-amendments/).

- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (http://www.nihr.ac.uk/policy-and-standards/research-passports.htm).

- TASC R&D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.

Version 6.0 – 16/02/16 - 1 -
• Notification to TASC R&D Office of any change in funding.
• As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.
• All eligible and adopted studies will be added to the UKCRN Portfolio database http://public.ukcrn.org.uk/. Recruitment figures for eligible and adopted studies must be recorded onto the Portfolio every month. This is the responsibility of the lead UK site. If you are the lead, or only UK site, we can provide help or advice with this. For information, contact Sarah Kennedy (01382 383882 or sarah.kennedy17@nhs.net) or Margaret Marshall (01382 383091 or margaret.marshall7@nhs.net).
• Annual reports are required to be submitted to TASC R&D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.
• Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.
• You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

Approved Documents

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<tr>
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<th>Version</th>
<th>Date</th>
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<td>15/07/2015</td>
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<td>CV – Joshua Muggleton (CI) (PI)</td>
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<td></td>
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<tr>
<td>CV – Katrina Johnston (AS)</td>
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<td>CV – Kenneth MacMahon</td>
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May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.

Yours sincerely

[Signature]

Elizabeth Coote
Head of Non-Commercial Research Services

TAYsle medical Science Centre (TASC)
Ninewells Hospital & Medical School
TASC Research & Development Office
Residency Block, Level 3
George Pirie Way
Dundee DD1 9SY
Email: liz.coote@nhs.net
Tel: 01382 383876  Fax: 01382 740122

c.c.  Margaret.marshall7@nhs.net
tasfeasibility.toyside@nhs.net
ken.mascna@ed.ac.uk
katrinajohnston@nhs.net