

*Université de Montréal*  
*Département de Psychologie, Faculté Arts et Sciences*

*“An Art, Not a Science”:*  
How do experienced clinicians differentiate autism from psychiatric conditions in adult women?

*Présenté par*  
Julie Cumin

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*Psychologie sous la direction de Laurent Mottron*

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*A été évalué par un jury composé des personnes suivantes :*

Tania Lecomte

*Présidente-rapporteuse*

François Lespérance

*Membre du jury*

Laurent Mottron

*Directeur de recherche*

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## Résumé et mots-clés

**Introduction.** Les femmes autistes sans déficience intellectuelle ni retard du langage ont une meilleure motivation sociale et des capacités langagières plus typiques que leurs homologues masculins. Ceci pourrait expliquer le sous-diagnostic des femmes autistes. Paradoxalement, l'autisme pourrait être surdiagnostiqué chez des populations psychiatriques avec des difficultés sociales. En effet, les critères de diagnostic demeurent assez larges, et cette condition relativement moins stigmatisée que plusieurs troubles psychiatriques. Il existe peu de directives pour les cliniciens hésitant à attribuer les difficultés adaptatives des femmes à (1) de l'autisme, (2) une condition psychiatrique, ou (3) les deux.

Les aspects qualitatifs de cette condition, absents des manuels de diagnostic, sont systématiquement identifiés par les cliniciens rompus à l'exercice du diagnostic de l'autisme. Ainsi, notre étude vise à mieux caractériser les difficultés liées à l'évaluation des femmes adultes pour un diagnostic d'autisme, ainsi que les traits, comportements et outils spécifiques utilisés pour différencier l'autisme de conditions psychiatriques.

**Méthodes.** Des entretiens semi-dirigés ont été effectués avec 20 psychiatres et psychologues experts en diagnostic de l'autisme chez les femmes, dans 7 pays différents. La méthode Framework a permis de révéler des thèmes adressant nos objectifs de recherche.

**Résultats.** Selon nos participants, les femmes autistes semblaient avoir appris certaines contingences sociales leur permettant de paraître plus typique, et la question du diagnostic différentiel se posait souvent. Les cliniciens effectuaient donc des entretiens flexibles et longs, et validaient les informations apportées par la personne. Plusieurs des traits cités comme indicatifs de l'autisme reflétaient une connaissance clinique de l'autisme. Le trauma, ainsi que le trouble de personnalité limite, étaient considérés comme particulièrement difficiles à départager de l'autisme.

**Conclusion.** L'évaluation pour autisme chez les femmes adultes présente des problématiques particulières que les cliniciens adressent en utilisant des boîtes à outils individuelles. Chez cette population, une capacité à proposer des pistes alternatives chez les personnes non-autistes s'étant auto-identifiées au spectre est primordiale.

Mots-clés : autisme, diagnostic différentiel, femmes, adultes

## Abstract and Keywords

**Introduction.** Autistic women present with greater social motivation and more typical language abilities than their male counterparts, leaving them vulnerable to misdiagnosis or late diagnosis. Paradoxically, there is concern about potential overdiagnosis of autism in psychiatric populations presenting with social difficulties, as diagnostic criteria remain relatively vague and autism less stigmatizing than many psychiatric conditions. Little guidance exists to guide clinicians when deciding whether to attribute adaptive difficulties in adult women to (1) autism, (2) a psychiatric condition, or (3) both.

Research suggests that autism is best reliably identified by expert clinicians having been exposed to a high number of autism cases, who notice qualitative aspects of the condition not included in diagnostic manuals. Thus, we aimed to better characterize the difficulties faced by clinicians in assessing adult women for autism, and the traits, behaviors and tools used to differentiate between autism and psychiatric conditions.

**Methods.** Semi-structured interviews were conducted with 20 psychiatrists and psychologists from 7 different countries, experienced in autism diagnosis of adult women. The Framework Method was used to reveal themes relevant to our research goals.

**Results.** According to participants, autistic women had learned certain social contingencies allowing them to appear more typical, which made differential diagnosis a frequent question. Clinicians recommended long, flexible assessments, and validating the information volunteered by the person. Many traits cited as indicative of autism reflected a clinical knowledge of autism. Trauma and Borderline Personality Disorder were cited as particularly difficult to differentiate from autism.

**Conclusion.** Evaluating for autism in adult women presents with singular challenges which clinicians address using individual toolboxes. In this population, it may be crucial to have the capacity to offer alternative avenues for non-autistic people having self-identified with the spectrum.

Keywords: autism, differential diagnosis, adult, women

## Abbreviations and Acronyms

**ADHD** Attention Deficit and Hyperactivity Disorder

**ADI-R** Autism Diagnostic Interview-Revised

**ADOS** Autism Diagnostic Schedule

**AQ** Autism Quotient

**ASD** Autism Spectrum Disorder

**BPD** Borderline Personality Disorder

**PTSD** Post-Traumatic Stress Disorders

## Dedication and Acknowledgements

To Sonata, where this all started

J'aimerais tout d'abord remercier mon superviseur, Laurent Mottron, qui a su m'orienter avec bienveillance, humour et empathie. À mes participants, je dis merci de m'avoir accordé leur temps malgré le contexte actuel. J'espère que ce travail vous sera utile dans votre pratique. J'ai eu la chance de côtoyer des étudiants, post-doc et chercheurs brillants qui ont tous apporté une perspective différente à mon travail, je remercie ainsi Alexia, Juliette, Valérie, David, Eya, Matthieu et Joséphine pour nos échanges et pour leur soutien. Un remerciement tout particulier à Noémie pour son travail sur les analyses. Merci aux Productions Spectrum de m'avoir rappelé pourquoi j'avais choisi ce domaine dans les moments difficiles, et au FRQS ainsi qu'au TACC pour leur soutien financier. Je remercie toute l'équipe de la ferme Cadet-Roussel, ainsi que Terra Perma, pour m'avoir accordé des lieux de rédaction magnifiques et inspirants. Maxime, qui a assisté aux hauts et aux bas de ces deux dernières années armé de chips et de grands discours d'encouragements. Enfin, un grand merci à ma famille, mes parents qui ont lu Neurotribes (en anglais !) pour mieux comprendre l'autisme, Baptiste et Alice pour votre soutien que je ressens même de loin.



# Literature Review

## Autism and the sex ratio

The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines autism as a neurodevelopmental condition characterized by (Area A) differences in social communication and interaction and (Area B) restricted and repetitive behaviors and interest. Autism is a life-long condition, with signs appearing in childhood and persisting into adulthood in the majority of cases. The notion of an autism “spectrum” came about in attempting to encompass a wide range of different phenotypes who nonetheless shared certain core characteristics. A wide variety of IQ, speech abilities, and support needs exist across the autism spectrum.

Across all phenotypical manifestations of autism, accurate diagnosis is incredibly important for several reasons. Firstly, access to services (social, medical, educational) usually requires a diagnosis. These services are often limited in quantity and may not be effective in improving quality of life in all who superficially present with signs that could resemble autism. For example, sociocommunicative difficulties could be attributable to autism, but also anxiety or speech-onset delay. Making an accurate differential diagnosis in such cases would have an impact on selecting an appropriate intervention. Secondly, accurate diagnosis of autism can provide relief for autistic people and their loved ones, particularly in adults who may have spent decades with no satisfying answer for their adaptative difficulties (Lewis, 2016a). Lastly, accurate diagnosis is of paramount importance to research, where over or underinclusive diagnostic criteria can hamper a better understanding of autism.

Prevalence of autism is estimated at around 1.5% (Fombonne, 2018). Though 15% of autism cases can be traced to a specific genetic mutation (syndromic autism) (Devlin & Scherer, 2012), 85% of cases are not associated with any specific genetic neurological disorder (non-syndromic autism). With no accurate biomarkers for autism, diagnosis mainly relies on behavioural observations by psychiatrists and psychologists, aided by standardized tools. The Autism Diagnostic Observation Schedule (ADOS) is widely used and includes 4 modules for use with people of different verbal abilities. The Autism Diagnostic Interview (ADI) is often used in conjunction and is a structured interview with parents to inquire about neurodevelopment. Other similar tools are the Developmental, Dimensional and Diagnostic Interview (3Di), the Diagnostic Interview for Social Communication Disorders (DISCO), Adult Asperger Assessment, and certain self-report questionnaires which are usually administered to adolescents and adults (Autism Quotient or AQ, Ritvo Autism Asperger Diagnostic Scale or RAAD). Despite our lack of understanding of genetic causes, non-syndromic autism remains highly heritable, with MZ twin studies indicating around 90% heritability (Sandin et al., 2017). Biogenetic factors in autism also result in higher prevalence in males (beyond the scope of this thesis), but where this male:female ratio truly lies has long been a contentious topic.

Leo Kanner's seminal 1943 paper (*Autistic Disturbances in Affective Contact*) described 11 children with speech-onset delays, restricted and repetitive behaviors and interests, and differences in social reciprocity and sensory specificities (Kanner, 1943). Of these 11 children with very noticeable difficulties, 3 were girls. Hans Asperger published a paper just a year later in which he described children who exhibited many similar behaviors and interest, with one key difference. These children had developed speech at a typical age, and indeed many had high verbal IQs (Asperger, 1991). The children Asperger described were all boys. Already, it appeared as though observations of autistic girls centered around those who had noticeable delays in developing speech and/or intellectual disabilities.

Whilst approximately 4 boys are diagnosed with autism for every girl, population samples have found lower sex ratios ranging from 2:1 to 3:1 (Loomes et al., 2017), suggesting gender-based diagnostic disparities. When analysed by autistic phenotypes, it would appear that, as per Kanner and Asperger's observations, discrepancies in the sex ratio are largely found in autistic people with no speech-onset delay and no intellectual disability, formerly known as Asperger's Syndrome (Loomes et al., 2017).

### **Underdiagnosis of autistic girls and women**

In 1981, an epidemiological study was one of the first to put forward hypotheses for this discrepant sex ratio across different presentations of the condition. The first was that, as in with some other conditions, girls were genetically protected from developing the condition, but that those who did develop autism were impacted "relatively more severely" (Wing, 1981). The other hypothesis put forth by this paper was that autistic girls of typical intelligence were somehow being missed in the search for cases, perhaps because superior verbal abilities typically found in girls were also present in autism, thereby making diagnosis based on communication deficits more difficult (Wing, 1981).

Research over the past decades has suggested that a hybrid of these explanations may help us to understand the sex ratio. Population samples have indeed confirmed that a "female protective effect" may be at play (Loomes et al., 2017; Werling, 2016), but also that autistic women were at particular risk to be missed or misdiagnosed. Clinicians described young girls with higher social motivation than their male counterparts (Attwood, 2007) who did not quite fit the clinical criteria for autism because they possessed good social mimicry, despite not understanding the rules of neurotypical interactions underlying these behaviors (Kopp & Gillberg, 1992). These abilities could "obscure the core deficit to a considerable extent" such that clinicians would not suspect autism (Kopp & Gillberg, 1992).

Research into why girls and women with no speech-onset delay and no intellectual disabilities are diagnosed at lower rates and later than their male counterparts has largely taken off over the past decade. This work has in part focused on comparative research between autistic men and women on a range of measures. The existence of a "female phenotype" of autism is still debated. Comparative research has not thus far conclusively proved that significant differences exist

between autistic men and women on core signs of autism, executive function or various aspects of cognition. Many sex differences reported in autism are also found in the general population, such as higher reported sensory sensitivity (Dixon et al., 2016; Lai et al., 2011), or greater social motivation (Sedgewick et al., 2016). However, a 2014 meta-analysis found no significant differences in the social behavior and communication domain of DSM-4 symptomatology between boys and girls (Van Wijngaarden-Cremers et al., 2014). A recent meta-analysis and systematic review of behavioral and cognitive sex/gender differences in autism concluded that “individuals with autism are fundamentally similar to typically developed individuals in regard to their sex/gender variation in core autism characteristics” (Hull, Mandy, et al., 2017).

With inconclusive evidence for a distinct female phenotype based on comparative studies of autism signs and cognition, much research has shifted to focusing on the phenomenon of masking or camouflage. Though not exclusive to women (Hull, Petrides, et al., 2017), or to autism (Begun & Kattari, 2016), camouflaging has come to be associated with autistic women of typical intelligence due to high self-report of camouflaging. Camouflage has been operationalised in different ways, with a general definition being the process of trying to “pass” as neurotypical. Qualitative research has translated clinical observations that autistic women appeared more socially motivated into more systematic characterisations of this phenomenon. Camouflaging has been self-reported both in late-diagnosed autistic women (who presumably would have in part been missed in childhood because of this) (Bargiela et al., 2016) and in girls diagnosed in childhood and early adolescence (Tierney et al., 2016). Remarkable consistency is seen across these accounts, with participants detailing the great amount of energy they put into trying to appear neurotypical, by observing and mimicking their peers, analysing films and TV shows, or rehearsing social scenarios ahead of time (Bargiela et al., 2016; Hull, Petrides, et al., 2017; Milner et al., 2019; Tierney et al., 2016). Participants also unanimously identified the mental cost of attempting to camouflage their autism, citing that it caused exhaustion and a loss of self-identity.

Research attempting to measure camouflage has run into issues of definition and methodology (Fombonne, 2020). Indeed, both tools developed to measure camouflaging behaviours actually quantify perceived *efforts* to appear neurotypical (Hull et al., 2019; Livingston et al., 2020). Defined as such, it is unclear that camouflaging would lead to delayed diagnosis (Livingstone et al. found no correlation with age of diagnosis), because it does not measure how successful the camouflaging is.

A line of research has alternatively defined camouflaging as the discrepancy between observed social behaviours on a standardized autism assessment (ADOS), and people’s self-reported autistic traits (Autism Quotient, AQ). Indeed, one study found higher discrepancies in ADOS-AQ scores for autistic women when compared with autistic men (Lai et al., 2017). This definition rests on the assumption that the AQ is a measure of “true” autism, when it has been established that this measure can be affected by a number of factors, notably psychiatric comorbidities (Dudas et al., 2017; Ketelaars et al., 2008). It also assumes that clinicians base their appraisal of autistic people’s social skills off of ADOS scores. Lastly, is not clear that this difference cannot be explained by typical sex differences.

As an alternative, “behavioural camouflage” research has sought to demonstrate the specific means by which girls and women may appear more typical. For example, research into autistic girls’ narrative skills may explain how they could perform better on the ADOS storytelling task. Indeed, research has suggested that autistic girls are better able to fill in pauses in a conversation compared to autistic boys (Parish-Morris et al., 2017), and use more words indicating an awareness of others’ internal states than their male counterparts (Boorse et al., 2019). Recent research has nuanced these findings, by looking into the first impressions that autistic people make on untrained assessors. Following 5 minute interactions with autistic and typically developing boys and girls, confederates rated their conversations with autistic boys more negatively than with typically developing boys and girls, and autistic girls (Cola et al., 2020). Conversations with autistic girls were rated as positively as those with typically developing children and adolescents, despite being matched with the male sample for sociocommunicative difficulties on the ADOS. These studies make the case for careful interpretation of scores on standardized assessments which may be artificially inflated in girls, and for assessment by an expert clinician.

Whether there is enough evidence to make the case for a sexually dimorphic phenotype of autism or typically sex differences also present in autism, epidemiological studies still suggest that autistic girls and women are underdiagnosed. Clinicians and researchers have suggested two solutions to better capture these cases: gender-specific screening and assessment tools, and gender-specific cutoffs on existing tools. A study indeed demonstrated that, in boys and girls who obtained high scores on an ASD screening tool, 56% of boys went on to obtain diagnosis, compared to 38% of girls (Constantino & Charman, 2012). Girls who obtained diagnosis had more intellectual and behavioural difficulties, which taken together suggested that girls with similar levels of autism symptomatology needed to display comparatively more difficulties than boys to obtain the same diagnosis. For this particular screening tool (the Childhood Autism Spectrum Test), it is of interest to note that, in the general population, 3x more boys obtain high scores than girls. A high score in a girl should therefore be more cause for concern, when compared to the general population.

Alternatively, gender-specific screening and assessment tools take into account qualitative descriptions of how autistic females may differ from males. For example, the Girls Questionnaire for Autism Spectrum Conditions (Ormond et al., 2018) acknowledges that imaginative play may be present in autistic girls, and that girls and women may present with special interests of a qualitatively different nature that superficially appear more typical (Hiller et al., 2014). The intensity and time dedicated to the interest is still present, but the subject of interest may take the form of animals, music or celebrities.

## **Autistic traits and complex clinical presentations**

Though autistic girls and women of typical intelligence may receive late diagnoses (or none at all) through the aforementioned mechanisms, research suggests that they nonetheless will often access mental health services (Au-Yeung et al., 2018; Bargiela et al., 2016). Indeed, research has suggested that autistic women may be doubly vulnerable to certain life events which affect autistic people and women at higher rates, such as abuse (Vide Ohlsson Gotby et al., 2018), job insecurity and underemployment (Baldwin et al., 2014; Taylor & Seltzer, 2011; Tint & Weiss, 2017),

and inadequate access to healthcare (Tint & Weiss, 2017). Qualitative research has for example found that chronic experiences of social rejection could facilitate autistic women entering into abusive relationships or failing to recognize the signs of an abusive partner (Bargiela et al., 2016; Milner et al., 2019).

In such cases, it appears that clinicians may be more likely to attribute the difficulties of autistic girls and women to other diagnoses more frequent in females, such as depression, social anxiety, eating disorders or borderline personality disorder. Indeed, many autistic women report having received a diagnosis that only partially explained their difficulties (Au-Yeung et al., 2018, p.). For example, a diagnosis of autism alongside a diagnosis of depression might heavily influence treatment decisions, as expressed by this participant in a qualitative study on misdiagnosis:

I have expressed that I feel my depression is only a result of my, kind of, 'untreated autism' in effect. Meaning, that if I can find help through relevant counselling, connecting with others, to accept and understand the autistic side of me and discover what my real needs are then I have a chance at learning a new vocabulary to express those needs and this will greatly reduce the resultant mental health issues. (Au-Yeung et al., 2018, p.)

Autistic women have also reported having received a sole diagnosis of an eating disorder, which did not entirely explain their particularities. Indeed, studies have suggested that around one quarter of women with anorexia nervosa meet criteria for autism, even when evaluated whilst in recovery and using gold-standard assessment procedures (Westwood et al., 2017). Certain specificities found in autism, such as food intolerances, sensory specificities surrounding food and textures, cognitive rigidity, need for predictability/routines and interoceptive difficulties could superficially resemble anorexia, especially as this condition is more frequent in women than autism. However, qualitative research suggests that, in autistic women presenting with anorexia-like traits, body image does not appear to be the primary concern (Brede et al., 2020). Rather, eating difficulties are more linked to an attempt to gain control and respect a routine. As such, certain researchers have suggested that these types of eating difficulties may be better referred to as Avoidant/Restrictive Food Intake Disorder (ARFID), a restrictive ED not tied to body image concerns. In autistic women, anorexia can therefore be complex to disentangle from autism. There may be cases in which a single diagnosis of autism would explain eating difficulties, and cases where a primary diagnosis of autism with a secondary diagnosis of anorexia or ARFID would be appropriate. The key is not to miss the autism, as this may have crucial implications in the treatment of eating difficulties (Kinnaird et al., 2019).

Alternatively, autistic women may be entirely misdiagnosed with mental health conditions they do not have, such as Borderline Personality Disorder (BPD) (Au-Yeung et al., 2018). Borderline Personality Disorder is characterized by an extreme fear of abandonment, black and white thinking (e.g. attributing people's intentions as either all good or all bad), difficulties with regulating one's actions (high rates of substance use and risky sexual conduct), and emotions (feeling both positive and negative emotions intensely) and a disturbed sense of identity. Self-injury and suicidal behavior are high in this group, as are depression and anxiety. BPD does not in itself involve difficulties with

social cognition and theory of mind. Maintaining interpersonal relationships can however be difficult. BPD is a serious and stigmatizing diagnosis (Nehls, 1998).

BPD is primarily diagnosed in women and can be triggered by childhood abuse (Cattane et al., 2017). Indeed, chronic experiences of trauma, as may be the case when one experiences repeated abuse or bullying, can give rise to difficulties with emotional regulation, problems with social relationships and dissociation (Del’Osso et al., 2015). Thus, the issue of making a differential diagnosis between autism and BPD appear to singularly impact women. Research has noted overlap between the two conditions, for example in the form of case studies (Trubanova et al., 2014). Clinicians note that cognitive rigidity seen in autism may be confused for “black and white thinking” as seen in BPD, and that self-harm and difficulties with emotional regulation are also seen in both conditions (Ingenhoven, 2020; Rydén et al., 2008; Trubanova et al., 2014).

The following demonstrates a phenotype which may be difficult to attribute to autism or BPD, because it simultaneously involves a manipulative understanding of social relationships indicative of attachment issues, and a lack of flexibility in adherence to rules:

“Specifically, Carina indicated that she purposely did not communicate feelings of sadness to her friends because she was interested in seeing which of her friends would notice or intuit that she was feeling down and subsequently express concern. She reported that she always questioned the validity of her friendships with specific people if they did not pass her “friendship test.” (Trubanova et al., 2014)

A study involving self-report measures of autistic traits showed “heightened autistic traits in people with BPD” (Dudas et al., 2017). It is however important to note that heightened “autistic traits” are found in many other populations (Freeth et al., 2013; Reiersen et al., 2007), and may simply reflect general difficulties with interpersonal relationships (which are found across most psychiatric populations). This study also found no statistically significant difference on Autism Quotient scores between the BPD and autistic groups, but found that a third group diagnosed with both conditions had significantly higher scores than those diagnosed solely with BPD. Rather than suggesting that people with BPD have heightened autistic traits, it could be that the Autism Quotient is unequipped to properly differentiate between the two conditions.

Assessing for personality disorders across a sample of 54 autistic participants with no intellectual disability, researchers found no incidence of BPD (Lugnegård et al., 2012). A similarly designed study found some incidence of BPD in women, but this group included both Asperger’s Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), a diagnosis which could include people with developmental differences following childhood trauma (Hofvander et al., 2009). Lastly, a study investigated prevalence of autism in a sample of 41 female patients with BPD (Rydén et al., 2008). Participants were assessed for BPD by expert clinicians with specific experience in personality disorders. Participants were then assessed for autism “considering criteria for autism, Asperger’s Syndrome and PDD-NOS” by researchers, not expert clinicians. Findings that 15% of participants met criteria for autism are therefore to be interpreted with caution and may also

indicate elevated autistic traits but not necessarily an actual diagnosis. The overlap between autism and BPD, and whether or not the two conditions can even co-occur, remains unclear.

Differential diagnosis in autistic women and girls therefore present with singular challenges, whereby clinicians must disentangle elevated autism traits from an autistic condition, and decide whether to attribute adaptive difficulties to autism, a psychiatric condition, or both.

## **Overdiagnosis of autism**

Awareness of these issues of underdiagnosis, misdiagnosis and differential diagnosis in adult women has grown extremely rapidly over the past decade, eventually becoming its own area of research. The issue of underdiagnosis of autistic women and girls has been heavily mediated over the past decade, and certain scientific journals have dedicated issues to this topic. The DSM-5, published in 2013, includes a short section questioning the oft-cited 4:1 sex ratio in autism, advising clinicians that girls could present with seemingly milder social and communicative differences. In November of 2017, the United Nations drafted a resolution specifically addressing the additional difficulties faced by autistic girls and women, including access to diagnosis. In April of 2018, “Empowering autistic girls and women” was the official theme of the UN’s Autism Awareness Month. The underdiagnosis of autistic women has progressively become a topic of interest in research and in the media, for example warranting investigative pieces in *The Atlantic* (Mandavilli, 2015). It is often cited as an example of gender-based disparities in medicine.

Simultaneously, recent research has begun to suggest that current DSM-5 criteria of autism, when applied without clinical judgement, could be one of the reasons for ever-increasing prevalence of autism. This would suggest that children with certain conditions which can superficially present similarly to autism, such as ADHD or Social Communication Disorder, may be receiving autism diagnoses. In children, approximately 1/5 of ADHD cases will score positively on the ADOS. A recent meta-analysis indeed found that effect sizes of studies comparing autistic and non-autistic participants have steadily decreased over the past decades, with the authors attributing these results to overinclusive diagnostic criteria (Rødgaard et al., 2019). The same results were not found in schizophrenia, suggesting that the mechanisms of this change are proper to autism, and not due to better tools or diagnostic capabilities. Furthermore, pressure to diagnose children earlier and earlier may contribute to overdiagnosis. One study found that 30% of their sample of children diagnosed before age 3 went on to lose their autism diagnosis or have it replaced with another condition when re-examined a year later (Kleinman et al., 2008), with population-based research confirming that children diagnosed before the age of 2 and a half were more likely to lose their diagnosis than those assessed later (Wiggins et al., 2012). Lastly, a population-level survey study in Sweden found that the number of autism symptoms required to obtain the diagnosis has progressively decreased over the past 20 years (Arvidsson et al., 2018). Dysfunction scores remained constant throughout, and the authors noted the possibility that clinicians were more likely to assign a diagnosis of autism in cases where the presentation was ambiguous but the patient had a real need for services.

Little research exists to corroborate this trend in adults, but clinicians have authored pieces hypothesizing that similar patterns may be occurring. Autism is relatively less stigmatizing than many

psychiatric conditions, and has benefited from increasingly positive coverage over the past few years. Combined with increasing awareness of underdiagnosis in women, it is possible that the pendulum may swing the other way. Clinicians hesitating to attribute their patients' social difficulties to stigmatizing labels such as personality disorders may be tempted to give a diagnosis of autism, bolstered by the fact that DSM criteria for social difficulties are extremely vague (Nylander, 2015). Self-diagnosis of autism has become frequent, in part due to long waiting lists for diagnosis and immense access to information about autism through the internet (Lewis, 2016, 2017).

Case studies have reported instances of adult women losing their autism diagnosis when re-evaluated by autism experts, in favor of diagnoses such as depression, BPD and ADHD (Tak, 2020). Notably, the authors specifically mention certain signs of autism which are found in other conditions. For example, poor eye contact may be present in social anxiety and depression, "restricted interest" in another person could be the result of attachment difficulties, and sensory differences are often found in ADHD. The authors note that it seems as though previous clinicians had not considered other explanations for observed symptoms, and had not conducted a thorough developmental history, for none of the cases showed clear signs of autism in childhood. A commentary warns that such diagnostic mistakes may also be extremely detrimental to patient mental health (Ingenhoven, 2020).

### **Diagnostic "gold-standard": clinical expertise**

Therefore, we consider that autistic women are specifically at risk for underdiagnosis and misdiagnosis, and that overdiagnosis may also be an issue in adult populations. In this current context where screening tools and diagnostic criteria appear unable to reliably give us diagnostic boundaries, it is imperative to better define the criteria which differentiate autism from psychiatric conditions in adult women.

This research project rests on findings that expert clinicians are able to recognize autism by referring to their knowledge of a behavioral phenotype acquired with experience and can do so better than the DSM criteria as they are currently formulated. Multidisciplinary, expert assessment is considered the gold-standard when evaluating for autism. Expert clinicians have better inter-rater reliability on autism diagnosis when they are allowed to make use of this clinical acumen, rather than using a standardized checklist of symptoms (Klin et al., 2000). Behavioral phenotyping research suggests that expert clinicians (having diagnosed over 200 autistic people) incorporate signs of autism not included within the DSM, such as gait and prosody (de Marchena & Miller, 2017). In order to better understand what differentiates autism from psychiatric conditions in women, one possibility would be to examine how expert clinicians make diagnostic decisions in this population.



## Article for Submission

*“An Art, Not a Science”:*

*How do experienced clinicians differentiate autism from psychiatric conditions in adult women?*

Julie Cumin<sup>1,2</sup>, Laurent Mottron<sup>2,3</sup>

1. Université de Montréal, Département de Psychologie, Faculté Arts et Sciences
2. CIUSSS du Nord-de-L'Île de Montréal, Hôpital en santé mentale Rivière-des-Prairies
3. Université de Montréal, Département de Psychiatrie, Faculté de Médecine

To be submitted to the Canadian Journal of Psychiatry (first choice) or Autism (second choice)

## Background

Autism is a neurodevelopmental condition which manifests in childhood, characterized by differences in social communication and interaction, and intense and repetitive behaviors and interests. With no accurate biomarkers for autism, diagnosis mainly relies on behavioral observations, aided by standardized tools such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI). Biogenetic factors in autism do result in higher prevalence in males (Werling, 2016), but where this male : female ratio truly lies has long been a contentious topic. Whilst approximately 4 boys are diagnosed with autism for every girl, population samples have found lower sex ratios ranging from 2:1 to 3:1 (Loomes et al., 2017), suggesting gender-based diagnostic disparities. When analysed by autistic phenotypes, it would appear that, as per Kanner and Asperger's observations, discrepancies in the sex ratio are largely found in autistic people with no speech-onset delay and no intellectual disability, formerly known as Asperger's Syndrome (Loomes et al., 2017).

It was suggested early on that autistic girls of typical intelligence were somehow being missed in the search for cases due to superior verbal abilities typically found in girls, which made diagnosis based on communication deficits more difficult (Wing, 1981). Clinicians described young girls with higher social motivation than their male counterparts (Attwood, 2007) who did not quite fit the clinical criteria for autism because they possessed good social mimicry, despite not understanding the rules of neurotypical interactions underlying these behaviors (Kopp & Gillberg, 1992). These abilities could "obscure the core deficit to a considerable extent" such that clinicians would not suspect autism (Kopp & Gillberg, 1992). However, the existence of a sexually dimorphic phenotype of autism is still debated. Many sex differences reported in autism are also found in the general population, such as higher reported sensory sensitivity (Dixon et al., 2016; Lai et al., 2011), or greater social motivation (Sedgewick et al., 2016), and a recent meta-analysis and systematic review of behavioral and cognitive sex/gender differences in autism concluded that "individuals with Autism Spectrum Conditions are fundamentally similar to typically developing individuals in regard to their sex/gender variation in core Autism Spectrum Conditions characteristics" (Hull, Mandy, et al., 2017).

With inconclusive evidence for a distinct female phenotype, much research has shifted to focusing on the mechanisms by which girls and women on the spectrum may go unnoticed. Heightened social motivation in girls and women may facilitate conscious and unconscious "masking" of autism signs in an effort to fit in. Camouflaging has been self-reported both in late-diagnosed autistic women (who presumably would have been missed in childhood partly because of this) (Bargiela et al., 2016) and in girls diagnosed in childhood and early adolescence (Tierney et al., 2016). Remarkable consistency is seen across these accounts, with participants detailing the great amount of energy they put into trying to appear neurotypical, by observing and mimicking their peers, analysing films and TV shows, or rehearsing social scenarios ahead of time (Bargiela et al., 2016; Hull, Petrides, et al., 2017; Milner et al., 2019; Tierney et al., 2016). Participants also unanimously identified the mental cost of attempting to camouflage their autism, citing that it caused exhaustion and a loss of self-identity.

Research has also demonstrated the specific skills which may allow autistic girls and women to appear more typical both to clinicians and naïve observers. Autistic girls have more typical narrative skills than autistic boys as measured on the ADOS storytelling task (Boorse et al., 2019; Parish-Morris et al., 2017), and are rated more positively than autistic boys by naïve confederates following a 5 minute conversation, despite equal ratings of sociocommunicative difficulties from an experienced clinician (Cola et al., 2020). These studies make the case for careful interpretation of scores on standardized assessments which may be artificially inflated in girls, and for assessment by an expert clinician.

Though autistic girls and women of typical intelligence may receive late diagnoses (or none at all) through the aforementioned mechanisms, research suggests that they nonetheless will often access mental health services (Au-Yeung et al., 2018; Bargiela et al., 2016). In such cases, it appears that clinicians may be more likely to attribute the difficulties of autistic girls and women to other diagnoses more frequent in females, such as depression, social anxiety, eating disorders or borderline personality disorder. Indeed, many autistic women report having received a diagnosis that only partially explained their difficulties (Au-Yeung et al., 2018, p.). For example, qualitative research suggests that, in autistic women presenting with anorexia-like traits, body image does not appear to be the primary concern (Brede et al., 2020). A combined diagnosis of autism and a restrictive eating disorder could therefore be important when considering treatment options (Kinnaird et al., 2019).

Alternatively, autistic women may be entirely misdiagnosed with mental health conditions they do not have, such as Borderline Personality Disorder (BPD) (Au-Yeung et al., 2018). Self-harm and problems with interpersonal relationships are frequent in both BPD and autism, making the two conditions complex to disentangle (Trubanova et al., 2014). Though research has found heightened self-reported autistic traits in people in BPD (Dudas et al., 2017), assessing for personality disorders across a sample of 54 autistic participants with no intellectual disability, researchers found no incidence of BPD (Lugnegård et al., 2012). The overlap between autism and BPD, and whether or not the two conditions can even co-occur, therefore remains unclear.

Little guidance exists for clinicians assessing adult women for autism. Standardized autism diagnostic and screening tools are not normed to consider gender differences in autism, and may lack specificity. In children, approximately 1/5 of ADHD cases will score positively on the ADOS. A recent meta-analysis indeed found that effect sizes of studies comparing autistic and non-autistic participants have steadily decreased over the past decades, possibly due to overinclusive diagnostic criteria (Rødgaard et al., 2019). Clinicians hypothesize that overinclusive diagnostic criteria for autism may similarly impact adult populations, making it easier to attribute social difficulties to autism rather than a more stigmatising diagnosis (Nylander, 2015). Case studies have reported adult women losing their autism diagnosis when re-evaluated by autism experts, in favor of diagnoses such as depression, BPD and ADHD (Tak, 2020).

Assessing adult women for autism therefore poses singular challenges, wherein clinicians must ask themselves whether a person's difficulties are best explained by autism, a psychiatric condition, or both. In the absence of clear clinical guidelines and tools, one option may be to

investigate the decision-making process by which expert clinicians confirm or exclude a diagnosis of autism in adult women of typical intelligence.

This research project is based on the assumption that expert clinicians are able to recognize autism by referring to their knowledge of a behavioral phenotype acquired with experience and can do so better than DSM-5 criteria as they are currently formulated. Multidisciplinary, expert assessment is considered the gold-standard when evaluating for autism. Expert clinicians have better inter-rater reliability on autism diagnosis when they are allowed to make use of their clinical acumen, rather than using a standardized checklist of symptoms (Klin et al., 2000). Behavioral phenotyping research suggests that expert clinicians (having diagnosed over 200 autistic people) incorporate signs of autism not included within the DSM, such as gait and prosody (de Marchena & Miller, 2017). Expert clinicians, when asked about their observations of gender differences in autistic children, came to the conclusion that the condition presented in a way which was, “Exactly the same but completely different” across gender (Mugleton et al., 2019). Expert clinicians saw autism as a gender-neutral condition which affected boys and girls to the same degree, but was overlaid by typical gender differences to be taken into account. More interestingly, clinicians implicitly and subjectively hierarchised autism signs based on their experience of which signs were pathognomonic. In order to better understand what differentiates autism from psychiatric conditions in women, one possibility would therefore be to examine how expert clinicians make diagnostic decisions in this population. No such research has been undertaken in adults.

## Research questions

The principal questions this study seeks to explore are:

1. What complexities arise when assessing adult women for autism?
2. Which traits and behaviours do expert clinicians seek out when assessing adult women for autism?
3. Which tools and techniques do expert clinicians use to bring these traits and behaviours to light?

## Methods

### Participants

Participants were 20 clinicians with extensive expertise diagnosing autism. A behavioral phenotyping study looking into clinical expertise in autism defined “expert” as someone having been exposed to at least 200 autism cases, which was the median number of cases in their sample (de Marchena & Miller, 2017). We however wanted to ensure particular exposure to diagnosis of adult women. Therefore, our inclusion criteria were (1) to be a clinician participating in the autism evaluation process (alone or within a team), (2) who had diagnosed at least 200 autistic people over the course of their career, (3) including at least 100 autistic women.

Clinicians from all countries were able to participate if they were comfortable with an interview in French or English. It was ensured that no clinicians practiced within the same clinic or institution as another participant, in order to ensure a diversity of opinions on the topic.

Participants were recruited through Twitter, mailing lists of clinicians specializing in adult and/or female diagnosis, and word of mouth (clinicians recommending colleagues with similar expertise). Interested participants received an email (in English or French) to access an information and consent form on a secure data collection platform (RedCAP) administered by the CIUSSS de Nord de l’Île de Montréal. After signing the online consent form, participants were able to indicate their availabilities for a videoconference or phone interview. Upon submitting, participants viewed the 4 *a priori* issues that would be addressed during their interviews. 2 interviews were conducted by phone, and 18 by Internet videoconference.

Participant characteristics are described in Table 1 ([Appendix I](#)). 9 participants practiced as psychiatrists, 10 as clinical psychologists, and 1 as a Speech-Language Pathologist. 14 participants practiced in the private sector, and 6 in the public sector. 18 participants practiced in specialized autism services, whilst 2 practiced in general mental health services. The mean number of years diagnosing autism was 18.3 (SD=10). The mean number of adult female assessments per year was 35 (SD=19.5).

### Interview Schedule

A semi-structured interview schedule was developed specifically for this study, according to the research questions ([Appendices II and III](#)). An initial interview schedule was devised by the first and last author (a psychiatrist specialized in autism diagnosis), then refined with a qualitative methods expert (SP). The interview was designed to cover four main *a priori* issues according to the research questions. These issues were, (1) Factors contributing to a complex assessment, (2) Methods for running a complex assessment, (3) Traits and behaviors specific to autistic women, and (4) The process of deciding between alternative or cumulative (comorbid) diagnoses.

Three practice interviews were conducted by JC and SP with 1 member of the research team (CPH) and 2 clinical psychologists exterior to the research team. The interview schedule was further refined with feedback from these three test participants. The interview schedule was designed to be used flexibly, with questions asked in any order as subjects arose. All interviews began with questions on the participant’s experience diagnosing autism, and the procedure they used for assessments in

adult women of typical intelligence and verbal ability. The interview schedule was translated into English by JC, and translations refined and validated by two bilingual autism clinicians.

## Data Analysis

All interviews were transcribed verbatim by a transcription service. The Framework Method was selected for data analysis as it is highly structured and therefore appropriate for projects involving several researchers, and also allows for a hybrid of inductive and deductive coding, making it particularly suited for the analysis of semi-structured interviews where research objectives are clear but participant data may alter the a priori issues identified (Gale et al., 2013).

The 6 steps of the Framework Method were rigorously followed: (1) Transcription, (2) Familiarisation, (3) Coding, (4) Developing an analytical framework, (5) Applying the analytical framework, (6) Charting and summarizing the data.

First author JC led the analyses, first reviewing all transcripts to ensure that acronyms and jargon were correctly transcribed, and reading through the transcripts several times. First author JC and last author LM open coded the first half of the interviews, to ensure that important aspects of the data were not missed. A working analytical framework was developed by JC based on these codes, which was checked for face validity with last author LM and co-author ABC. The second half of the interviews were then coded by a research assistant using this framework, in order to add a third perspective on the data. A consensus approach was used between the three people involved in coding, to iteratively refine the analytical framework. NVivo 12 was used to chart the data onto the themes, allowing for frequency tables to be generated and illustrative quotations to be selected.

## Results

16 themes were identified in the data across the 4 a priori issues explored in the semi-structured interviews, and are summarized in Table 2, along with their frequency ([Appendix IV](#)).

### Factors of complex assessments

This issue sought to identify the factors specific to both women and autism which made assessments more complex for clinicians and was split into 3 themes.

#### Camouflaging

Almost all clinicians invoked the fact that autistic women had learned certain social contingencies which could make them appear more typical (camouflaging), and this made it more difficult to observe whether social difficulties were present and autistic in nature. Some clinicians spoke of lengthy waitlists or expensive assessments which could place high expectations on an autism assessment, paradoxically increasing camouflaging behaviors:

Very often when they are smart, they are very often more anxious, more perfectionistic and have adapted so much more and want to do well that so many symptoms are masked.  
(Participant 16)

## Sociocultural Perceptions of Autism

Many clinicians identified that autism seemed to benefit from a less-stigmatising status when compared to psychiatric conditions. Most women being assessed were actively seeking an autism diagnosis, and in some cases it seemed a sought-after alternative to a stigmatising mental health condition, "It's this stigma that the personality disorder diagnosis brings. And interestingly they feel that autism is more socially acceptable." (Participant 12)

Participants described the important role that autism diagnosis could play in legitimizing people's sense of belonging to a community:

"I had one 62-year-old lady, she said to me after we said "yes we think it's autism", and she just went "I have found my tribe, this is where I belong"" (Participant 14)

There's something that we see in patients, perhaps more so with the women, and it's this need for belonging. It becomes an identity, the autism spectrum really is an identity, belonging to a group, it defines who you are in an important way. (Participant 09)

Participants working in specialized autism clinics highlighted the fact that information about autism was widely available on the internet, and that most women who came to them for an assessment had already self-identified with the condition:

They've maybe been online, and contacted lots of people, YouTube, whatever, they've accessed material, they might have joined online groups, and they've identified very strongly with the autistic characteristics. (Participant 04)

Many participants recognised that, "when people really strongly suspect this diagnosis in themselves and they have really looked into it, researched it, they are usually right" (Participant 15). However, some participants expressed that extensive research prior to appointments could make assessments more difficult:

They very often have a pretty clear belief or hope that they do have autism as opposed to the other diagnosis they might have. And so it's almost like that's the thing that might get in the way because we are trying to unpack what their experience is and not be biased by their belief. (Participant 11)

Some participants felt that this could be bolstered by broad information and testimonies available in the media and on the internet:

Many of our patients will go online, join groups on Facebook and self-identify as autistic based on the idea of, "I've always felt different". That's very typical. So we do have to tell people that it isn't a diagnostic criteria for autism to feel different. (Participant 01)

In some cases, participants reported having assessed women who had strongly identified with the condition to the extent that they were living their life as an autistic person:

She had made a friend who was autistic and she had started going along to the autism support groups, the ones that you can go to without a formal diagnosis and she felt



really welcome in that community and she was identifying with a lot of the things that people were saying about having been bullied and marginalized, and things like that.  
(Participant 21)

### Negative reactions

Over half of clinicians described reactions of disappointment when they did not diagnose a female patient with autism. Anticipating for this possibility and its effects on patient mental health was identified as a factor contributing to a complex assessment:

When I evoke the possibility of for example ADHD as a differential diagnosis, you really see that it doesn't legitimise their identity to the same extent that Asperger's Syndrome would.  
(Participant 02)

She didn't have any impairment on the kind of social / emotional understanding [...] but she was a victim of nasty, nasty bullying and marginalization. And when I said "this explains things" she was really angry and very disappointed because she had identified with the autistic group.  
(Participant 21)

## Managing a complex assessment

In order to address these difficulties, participants were asked about the adjustments made to their practice in order to determine whether the person's difficulties were attributable to autism, a psychiatric condition, or autism **and** a psychiatric condition.

### Multiple Tools

One clinician in our study based their assessment off scores on systematic assessments, with the rest using questionnaires they had developed themselves, unstructured interviews, and/or a mix of the three. Almost all clinicians advised against relying solely on the ADOS, and indeed any specific diagnostic tool:

Very often our women that we see are under cut-off on the ADOS and if you just took that at face value, you'd be saying they don't have autism but actually if you say to them after you've done the ADOS "OK how did you do that?" you then get a real sense of the difficulty they've got [...] It's unpacking. Not just taking whatever at face value but unpacking it, how they've done it. (Participant 13)

Many clinicians indicated working with many tools, to confirm or exclude different diagnostic hypotheses:

You need to think of several possibilities and rigorously eliminate them. Differential diagnosis is a funnel, "I have a list of 20 things, I put this in place to evaluate that, oh look option 12 is now gone!". It's not a highway, do the ADOS and the ADI-R and say "this is an autistic person". (Participant 8).

Clinicians disagreed on their use of self-report questionnaires. Some clinicians categorically did not administer them due to perceived low specificity, “The AQ is really obsolete. It just isn’t effective and I feel like anyone can find the answers they want online, it sometimes seems copy-pasted” (Participant 07). Other clinicians highlighted that actually contradictions in someone’s presentation compared to their self-reported autism trait scores provided valuable information, “Say somebody scores very high on the AQ-50 and you do not find any, in terms of structured assessment or clinical observation, not much around autism traits or signs of ASD, I think the question then for me as a clinician is why is there a gap or a discrepancy? It can be the person is over-reporting symptoms at one end of the spectrum, to the other end of the spectrum which is actually “I think I have difficulties in these areas” but probably they are not being picked up in most structured assessments” (Participant 18).

### Flexible and Long Assessments

One of the ways clinicians accounted for camouflaging of autism signs in adult women was to construct assessments in such a way that they would bring to light autism traits and behaviors. Lengthy assessments were cited as useful for this reason:

[The ADOS is] to look at whether she can sustain a conversation with an unfamiliar adult for more than three hours. So potentially with a high level woman, what I am looking for is at the end of that three hours, she may present as quite tired, she may present as having a slower process rate or be complaining of difficulty with concentration, things like that. (Participant 12)

Many clinicians purposefully did not standardize their assessments, as it allowed them to evaluate a person’s reaction when unable to prepare for an interaction:

I don’t let people just reel off their story, in a way that they could deliberately overprepare what to say, but as they tell their story and as I ask for specific elements in their childhood or their functioning, you do see a kind of narrative coherence emerging. (Participant 02)

So we are looking at what can they do with humor and banter and that sort of ironic talk in the room. (Participant 12).

### Validating Information

The second way clinicians accounted for camouflaging behaviors was by validating the person’s difficulties, both presently and in childhood. This was done by collecting as much prior information as possible from third parties to understand “Why is this person considered to be disabled?” (Participant 07). Prior relationships with healthcare providers were cited as important pieces of information in some cases, for example to understand why previous mental health intervention had been unsuccessful:

It's the counsellor who's recognizing, “I work with people all the time and this isn't working,” or “the way in which this person's communicating, or interpreting, or unable to express their emotions seems different. (Participant 04)

Clinicians also validated adaptive difficulties and autistic behaviors by requesting specific examples of the person’s idiosyncracies:

They're intelligent, they've read about it, they've looked at the videos, they've read the books, and you think, they know, and you've got to check, are they saying textbook answers, or are they giving genuine examples. (Participant 05)

Clinicians overwhelmingly stated that neurodevelopmental history and chronology was amongst the first things they looked at when assessing a person with a complex phenotype:

So autism for me is a neurodevelopmental condition. It has been there for a long, long time. Certainly it has been apparent for a long, long time to the person who is an adult. So if I am not able to cross-sectionally see that in an assessment session, I think for me what is more important is to look at the longitudinal perspective and if that is there, it's there. (Participant 18)

The problem with diagnosing women is if you only stick to the here and now, they've been overlaid by depression or marital problems or work relationships, you know, that then makes it really complex to figure out what's going on. (Participant 11)

However, clinicians disagreed on the best ways to obtain developmental information. For some clinicians, an informant having known the person in childhood was of paramount importance, especially in cases where an autistic phenotype was not completely clear:

It's made very clear that, yes we would see people who didn't have a parent, or maybe they're estranged from their parents, but that actually it can be quite difficult for me to complete the assessment if we don't have information from somebody who has known them in childhood. (Participant 04)

Other participants felt that parents were not always good informants for adults, "If they have been undiagnosed to adulthood then by definition, their parents are not really good at observations. (Participant 13), and that this was not usually possible to obtain anyways. Clinicians relied on the person's own retelling of their childhood in such cases.

Clinicians sought out a variety of developmental information to make differential diagnoses, most specifically looked for difficulties beginning in primary school:

Usually 6, 7, 8 years old, and not really being in tune with or in harmony with the social event. (Participant 05)

However, many clinicians mentioned that in autistic women, certain adaptive difficulties had not manifested until their teenage years:

Quite often the girls are developing somewhat typically until the wheels fall off. So it might be in high school where the social demands exceed their capabilities. (Participant 14)

Lastly, some clinicians also inquired about family history, indicating that they assessed a large amount of mothers seeking assessment following their child's autism diagnosis:

When I see a patient whose child has been diagnosed, I systematically will do the full assessment and not stop at the screening. I do find that when you've self-identified and on top of that have a first degree relative on the spectrum, it's a good idea to explore that. (Participant 08)

### Managing Negative Reactions

When denying a diagnosis to someone who strongly self-identified with autism, clinicians had different methods for mitigating this disappointment. Some clinicians stressed the importance of exploring the possibility that a diagnosis would not be obtained with the person before the assessment began, in order to understand whether this may negatively impact their mental health:

If we find that this isn't autism the person's going to find it hard, so we need to go into the assessment with a kind of a caveat of people that sometimes present with autistic-like features but it may not be. (Participant 4)

Many clinicians invoked the Broad Autism Phenotype (BAP) or autistic traits as a way to soften disappointment in women who did not obtain the diagnosis:

I say, "the diagnostic assessment is completing a 100-piece jigsaw puzzle, and there are certain essential pieces; the corner pieces or edging pieces, [...] but to have the diagnosis you need 80 plus. Now, the average person has only 10 to 20. Now, you have 75. It's more than the average number, but it's not enough to confirm the diagnosis. (Participant 6)

Some clinicians also spoke of the fact that functional disability had to be met in order to give a formal diagnosis, but that they would make use of the "subthreshold" notion of autism in people who demonstrated excellent compensation:

We might talk about the fact that as they said, you know, if we had seen you 10 years ago, we would have had a different picture. So the person feels validated because "I do have autism, it's just that I've put so much effort in myself that I am now subthreshold", so it kind of turns into a positive. (Participant 13)

However, several clinicians did not make use of notions of "subthreshold" autism, explaining that for them the diagnosis was categorical:

That's nonsense. It's like being a little bit pregnant. (Participant 15)

I think it's really unhelpful because it doesn't give them access to anything. It doesn't make a lot of sense to them. [...] What I do say though is that many autistic people are very, very wise [...] and they've got really useful practical advice on how to manage aspects of your life from an autistic point of view that are not going to hurt neurotypicals. (Participant 21).

Of clinicians who reported reactions of disappointment when they did not give the autism diagnosis, some mentioned the ability to explore other reasons for their clients' difficulties as a factor that could mitigate disappointment:

“Usually the ones that aren’t diagnosed it’s because it’s clearly ADHD and anxiety and that explains their difficulties and so that diagnosis in itself is helpful because they know they can find medication for it and they are going to get some relief.”  
(Participant 16)

Not all participants were however able to do this in the context of their practice, “In [the public sector] if you’re only commissioned to assess autism, you cannot then assess for the other things basically, the other neurodevelopmental conditions.” (Participant 5)

Almost all participants agreed that the most important factor in lessening disappointment was building good rapport with their patient and validating the difficulties that had brought them to seek out assessment, “We are never saying to them “you are normal”, we would be helping them think about what else is going on for them” (Participant 11). One clinician felt that low rates of disappointment in their practice was due to their use of “draft” reports:

“Often decisions are made about people’s lives without them having a say in it. And our view is “it’s your report, not ours, you should be OK with what we are saying about you and statements we are making about your life. And if you are not, let’s talk about that” (Participant 14)

## Signs Indicative of Autism

After explaining what made assessments particularly complex in the case of adult women and how they addressed this in their practice, clinicians were then asked about the specific traits and behaviours they personally ascribed value to when deciding whether to confirm or exclude a diagnosis of autism in adult women.

### Qualitative nature of social difficulties and interests

Clinicians looked at current signs of autism, especially in cases where a childhood informant was unavailable or unreliable. This often began by exploring the person’s understanding of neurotypical social rules:

What can still be helpful when assessing adult women, and this is difficult to contest, is spontaneity in social reciprocity. (Participant 02).

They only know they’ve overstepped the mark because somebody else told them rather than because they had realised. (Participant 11)

Many participants mentioned that they specifically looked for extreme fatigue following social activities, and the use of special interests to recover:

If there isn’t any social fatigue, or if the person tells me she recharges her batteries amongst other people, then it’s over I won’t diagnose autism, unless this person has best friends. So it’s subtle. (Participant 06)

Where social difficulties made it difficult to assess whether this understanding was present, some clinicians assessed whether restricted interests appeared to be autistic in nature. Autistic interests were seen as “soothing in some way” (Participant 15) as opposed to ego-dystonic, and “a transient obsession, which passes once it has been resolved” (Participant 07). Some clinicians specifically asked patients to elaborate on their special interests:

What about special interests, things that you’ve been obsessed with?”, and she went “ahh... number plates”. “What about car number plates, tell me all about that, tell me what you love about them?”. “I just like them”. “OK, but tell me all about them, it’s a big interest, I want to hear everything about them”. She couldn’t say anything because it wasn’t an interest, it was what she remembered from what she had read. (Participant 12)

One clinician conversely felt that, “the depth of interest isn’t really that important because so many people know a lot of things about many different things and deep interests change over time. It’s the way they are used as social currency.” (Participant 13)

After having collected developmental history and information on current functioning, some clinicians spoke of relying on a “feeling” that the person was autistic:

And it was something that my original supervisor talked to me about, using my awareness really about how the interaction feels. (Participant 10)

Really the first thing is more the clinical feeling that I’m dealing with someone like me. (Participant 13) \*Participant is autistic

#### Discrepancy between intelligence and personal/professional success

Many participants mentioned that autistic women presented as intelligent in different ways, despite a lack of personal/professional success, “Another thing I look for is if they seem obviously extremely intelligent but don’t seem to really have accomplished much in traditional ways in life.” (Participant 13)

This intelligence manifested emotionally, as clinicians pointed out that extreme empathy seemed to be a characteristic of autistic women. This also manifested through interests in social justice and an ability to recognize themselves in other autistic people:

I really have this impression that hyperempathy towards others but hypovigilance of their own emotions is quite typical of autistic girls. (Participant 2)

They are usually totally concerned about social justice. You have to say-, you wait for them to say something in the history and then you pursue it, about injustice and changing things. (Participant 13)

Autistic women have been able to conclude “I am autistic because I look like this person”. They can identify with others. The boys don’t have this ability. (Participant 7)

Participants also highlighted that autistic women had usually taken independent action to compensate for their difficulties, investing a great deal of effort into these attempts:

“They've had CBT for anxiety for many years and it's never helped, so they got stuck, and they've obviously been willing to look at issues and explore ways of improving their lives, but they just can't seem to get out of it” (Participant 04).

### Need for Prompting and Instructions

Some clinicians identified that autistic women required prompting and specific instructions when talking about themselves in a clinical interview:

They won't tell you about themselves unless you specifically ask. You have to say “cue: tell me more”. And then they will. It's not obedience it's more rigidity” (Participant 07)

One of the things I may do is ask them to bring in a photo album of their childhood. Now, photos are usually taken in social situations, so you then have an opportunity to discuss social situations [...] It's very useful as a prompt. (Participant 05)

### Asymmetry in social relationships

Many clinicians spoke of autistic women's relationships as asymmetrical for different reasons. One spoke of a lack of relationships with people their own age throughout their life:

I'll look for the mismatched peer relationships. “I always had friends”. “Really, were they friends from school in your age group or were they younger or older?” and it's always they were either much younger or much older. I've never met an autistic person who has true peer relationships. I certainly don't. My students think I'm so social and friendly, well I like teaching. I'm the teacher, they are the student, I like transferring information. There's no peer relationship. (Participant 13)

Other clinicians mentioned atypical understandings of friendships, for example identifying people in service jobs whom they saw regularly as their “best friends” (Participant 19), or the presence of a “resource person” (Participant 07), usually a parent, sister or childhood friend, whom they relied on for daily tasks and/or approval in social situations. This asymmetry and difficulties establishing and maintaining peer relationships was also identified as one of the mechanisms that could put autistic women at greater risk of being victims of abuse in relationships, “They might only realise they've been victimised years later. They don't have that perspective because there's no peer group to compare to” (Participant 02)

### Purpose of Diagnosis

Some clinicians highlighted that autistic women had a particular way of approaching the diagnostic process, which was rarely associated with wanting to gain access to services, but rather was driven by wanting to better understand oneself:

And we ask them “what difference will it make to you?” and women tend to say “I need to know who I am”. Men tend to want to use it like “well that's why I do that” and then they try to use that to justify behaviour. (Participant 12)

## Gender Identity Expression

Some clinicians mentioned that in autistic women, gender expression appeared more fluid, “I’ve seen that in a number of adolescent girls and young women, who are non-binary or trans in some way” (Participant 16). Clinicians alternatively mentioned that autistic women presenting as cisgender sometimes exhibited a “deliberately rehearsed femininity” (Participant 02):

Like they might be very well dressed and well made up, but then their fingernails will be dirty. There’s usually one thing that they’ve got wrong. They haven’t quite got it. (Participant 13)

## Alternative or Cumulative Diagnoses

This issue was explored with participants by discussing the diagnoses they found difficult to disentangle from autism, and the specific traits and behaviours clinicians looked for in such complex cases.

### Crisis Situations

When working with women currently in a mental health crisis, some clinicians felt it was in their patient’s best interest to delay making a decision about autism, in order to evaluate the person’s “baseline functioning” (Participant 07):

If I really have a hard time teasing it out, like is this just PTSD or is there autism too, I’ll be honest with them about that, and I will say, “ I know you have PTSD, there’s no question about that, but I think that if you can treat that and get that stable, and then come back for a consult, and we can look and see what’s left, [...] I’m going to hold off on the lifelong diagnosis and give you the one that I know is there. (Participant 09)

In depression you have a flat affect, you’re not very communicative, and sometimes the priority is to treat the depression, and then when that’s lifted, to see what’s underneath. (Participant 05)

### Trauma

15 participants stated that trauma, particularly in the early years, could lead to behavioral presentations resembling autism, making assessments particularly difficult:

The possible association between neurodevelopmental disorders and trauma makes differential diagnoses almost indiscernible. It completely blurs the presentation. (Participant 04).

It’s more simple if PTSD is linked to a single dated event, such as the patient saying I was the victim of a sexual assault at 16, and that’s when the symptoms started. (Participant 03)

Furthermore, many participants pointed out that autistic women themselves had often experienced trauma, but that many women who came to them for assessments had as well.



They're not mutually exclusive but can be a dual diagnosis. Those with ASD are prone to trauma, but especially the girls and women in terms of abuse in all its forms. (Participant 05)

### Borderline Personality Disorder

One of the differential diagnoses that was cited as difficult to make by most clinicians was Borderline Personality Disorder, which was sometimes conflated with issues of attachment and/or trauma:

Borderline personality disorder is the most complex. People come having been given that label and they are thinking it isn't BPD, it's something else [...] I would say probably it's more complex to unpack because if they have a history of trauma then they may very well have autism and a personality disorder, so it's trying to work out is it either, or, or actually is it both? (Participant 11)

One clinician felt that the two could be considered clinically opposite diagnoses:

One needs to be around people and is desperate not to be left alone, the other one needs time alone and doesn't particularly enjoy being around people. It's more complex when they have both, but when they don't have both it's very easy. They don't have abandonment issues, they don't think of suicide all the time, they don't have feel responsible for everyone else's behaviours and they don't dread abandonment. (Participant 13)

A few clinicians mentioned that gender bias could be playing a role in diagnosing personality disorders when assessing for autism, "They may have seen another clinician who said "you have borderline personality disorder because that's what women who cut themselves have" (Participant 15).

Some clinicians explained how an autistic woman could appear to have Borderline traits, through several mechanisms. One was relationships with other marginalized people, which could give rise to risk-taking behaviors (substance use, unsafe sex) that would appear to suggest BPD:

My impression is that there are situations where an ASD patient is there because it was her only way of fitting in – to socialize with other marginalized people in her class or her school. So she kind of copied their marginal strategies of substance use, tattoos, piercings, risky behaviours, so she might look borderline but it's not as polished. (Participant 03)

Another was having received a misdiagnosis of BPD and followed the recommended Dialectical Behavior Therapy treatment, leading a person to adopt the terms used in this therapy and speak of their own issues as though they had BPD:

Sometimes, people with autism have been diagnosed as borderliners, have been getting this therapy as borderlines, know a lot about borderline, and have been acting like borderline because that's what they have learned in therapy. (Participant 19)

The last was their scores on certain tools used to diagnose personality disorders:

A question on the MMPI might be, “I know who’s responsible for my problems, true or false?” and someone with autism will say it’s true and their answer is either I’m responsible for them or everybody else is responsible for them, but that comes out really high on the psychopathy scale because it measures egocentric thought. (Participant 09)

When attempting to differentiate BPD from autism in women, clinicians highlighted that the intentions and emotions behind diagnosis-seeking behaviours seemed of a different nature in autism and BPD.

People who come to see me saying “I did this and it means I’m autistic”, I’ll ask “Ok so why did you come to see me?” and in that moment we enter a debate to see how they argue. If the interaction is good quality, fluid, the person constructs arguments, seems angry, for me that’s not autism. (Participant 07)

Well when I say look autism just doesn’t make sense in this case, some of them will leave and slam the door, yell at their mother “You didn’t say what you were supposed to”, and just the way they communicate kind of proves that it’s not autism. (Participant 01)

Similarly to differential diagnosis, clinicians spoke of a “feeling” that a person was either autistic or had BPD:

Sometimes with people with personality disorder where you are in contact with them, they crawl under your skin. You feel in the dynamic that it’s doing something and I don’t feel that with autistic people. (Participant 20)

Clinicians spoke of traits which could superficially appear similar in both conditions, such as self-harm. However, numerous clinicians invoked that self-harm in BPD usually followed interpersonal conflict, whilst self-harm in autism was often attributed to sensory issues or changes to routines:

“If they have too many sensory issues they try to hurt themselves but it’s really just too much sensory information or too much social information and it’s their way of stopping you” (Participant 20)

Patients with ASD will have trouble explaining why, sometimes it’s a reflex or a routine, sensation seeking, or extreme stereotypy, a moment of frustration linked to something changing in their life” (Participant 08)

Clinicians spoke similarly of substance use, which in autism was not seen as serving to regulate emotions.

The reasons for difficulties with social relationships were also of a qualitatively different nature. One clinician mentioned that autistic women usually spoke of “difficulties with needing space” (Participant 10), and another spoke of ending friendships due to “lacking the social skills to deal with it, it’s confronting to deal with so they cut them off” (Participant 14) whilst women with BPD experienced relational difficulties due to “self-sabotaging because they are fearing that they are being abandoned” (Participant 14).

Understanding of neurotypical social dynamics was also seen as unimpaired in women with BPD, with one clinician pointing out “people with borderline have these mentalizing problems, but they have this when emotions are high. But when emotions are low, their theory of mind, empathising is very OK” (Participant 19). Another clinician added “They may have trouble establishing relations with others but it isn’t because they don’t understand them” (Participant 07).

Clinicians spoke of an ability to describe one’s emotions which was present in BPD, but less so in autism. Whilst women with BPD tended to “unfurl all of their different emotions (Participant 01), autistic women often found it difficult to identify their feelings and use varied language to do so:

The other thing we ask people is “can you name me five emotions apart from happy, sad and angry? Any other emotion apart from those three”. The average we get is two. And women tend to do very badly on that. (Participant 12)

## Discussion

This study used the Framework Method to qualitatively analyse semi-structured interviews conducted with 20 clinicians from 7 different countries. The Framework Method allowed for targeted exploration of 4 a priori issues with autism diagnosis in adult women of typical intelligence, as identified according to the scientific literature and knowledge gaps on this topic. Themes were then generated inductively according to the data. Participants had specific expertise assessing for autism in adult women of typical intelligence. Participants identified that autism assessment in this population could be difficult for reasons specific to women (camouflage, late diagnosis) and to autism (self-identification prior to assessment, negative reactions when diagnosis not obtained). In the absence of systematic guidance to address these complexities, participants described individual tools and techniques they had developed to assess adult women, and discriminate autism from psychiatric conditions.

This study involved perspectives from multiple cultural perspectives and contexts, different healthcare systems, and a range of clinical specialties and environments (general vs. targeted practice, public vs. private practice). Consistency across the main themes was found irrespective of these factors, including in countries where autism diagnosis is generally less funded and underdiagnosed. Clinical experts were involved at every stage of the research process to ensure that the semi-structured interview and data analysis reflected their clinical reality. However, data analysis was undertaken by two non-clinicians in order to avoid confirmation biases.

To our knowledge, this study is the first to (1) Explore challenges with assessing adult women for autism from the perspective of those performing the assessments, (2) Identify the specific tools, methods and behaviors used by expert clinicians when assessing complex cases in adult women. Clinicians largely identified the ways in which sociocultural perceptions of autism had impacted general diagnosis-seeking behaviors and how this could influence patient expectations. This is in line with research suggesting that self-diagnosis is particularly prevalent in autism. Previous research has identified that barriers to formal diagnosis of autism may bolster self-diagnosis particularly in minorities ([Lewis, 2016b](#); [Sarrett, 2016](#)). Our findings support this hypothesis, but add that relatively positive perceptions of autism compared to psychiatric conditions may also influence this phenomenon, with people self-identifying to a condition which may explain their social difficulties, and also legitimise their identity and sense of belonging to a community. Some clinicians highlighted that they noticed this need for belonging to a group more in their female patients. Heightened social motivation in women could therefore partly explain self-diagnosis of autism in female psychiatric populations.

Clinicians explained that part of the diagnostic assessment involved disentangling the person's expectations based on their research, from what clinicians recognised as autism following exposure to hundreds of autism cases. Virtually all clinicians mentioned reactions of disappointment when diagnosis was not obtained by the person being assessed. This aspect of diagnosis must be taken into account and managed, as it can result in depressive episodes or reactivate mental health

symptoms. Many participants in this study invoked “autism traits” and “subthreshold autism” as a means to lessen this disappointment by validating the person’s self-identification to an extent. However, whether clinicians assess for “autism or nothing” or “autism or something else” greatly depends on their comfort assessing other conditions, and the mandate imposed by their institution. One clinician hypothesised that self-identification to the spectrum in non-autistic people was not so much indicative of a “conviction of a diagnostic label” as it was “conviction about some difficulties that are not addressed at that point in time” (Participant 18). Seen as such, the ability to propose alternative avenues are of paramount importance when assessing complex adult cases in order to avoid iatrogenic damage. Other clinicians felt strongly that diagnosis was categorical, including one autistic participant. These clinicians felt that, in the absence of access to services, this was not helpful to their patients.

Though evolving societal perceptions of autism may influence patients during the diagnostic process, it is important to note that clinicians and researchers may also be influenced by media coverage of autism. This is demonstrated by the exponential interest in research on camouflaging despite the circularity of this hypothesis (Fombonne, 2020). The existence of a “female phenotype” is widely cited despite a lack of evidence that autistic women differ from men beyond typical sex differences found in the general population. How would defining autism according to two separate, sexually dimorphic manifestations of the condition ensure that core signs of the condition are still present across these phenotypes to such an extent that they can be referred to as a single diagnostic entity?

The gold-standard for autism diagnosis remains a qualitative one, as diagnostic procedures and behavioral phenotyping research suggest. Of the themes identified by our sample as heavily weighted towards autism in women, five were either not present in DSM-5 (Gender Identity Expression, Purpose of Diagnosis, Discrepancy between Intelligence and Success, Social Fatigue) or were a qualitative evaluation of a DSM-5 trait (Nature of social difficulties and interests). This is in line with research suggesting that expert clinicians integrate qualitative, non-verbal information into their assessments, such as gait and prosody (de Marchena & Miller, 2017).

Our study suggested that expert clinicians largely make use of individually developed techniques to reveal signs they see as most indicative of autism. However, qualitative does not mean entirely subjective, as the many points of agreement across participants in our study show, despite different sociocultural contexts and professions. This pattern detection effect could help to refine diagnostic criteria for autism, with a hierarchy of the relative importance of different autism signs to ensure that gender-based differences in presentation are taken into account. One option would be to triangulate the findings from this study by exploring the signs identified by clinicians in prototypical adult women. A prototype as here defined would be an autistic woman diagnosed with high clinical certainty by more than one expert assessor. The signs noticed by clinicians in this study, such as a diagnostic assessment geared towards self-understanding as opposed to access to services, or difficulty developing true peer relationships, could be evaluated and hierarchised by frequency in order to guide less experienced clinicians.

Lastly, the overlap between autism, trauma and Borderline Personality Disorder presented challenges even for experienced clinicians, suggesting that training and exposure to BPD may be important for clinicians assessing adult women for autism. Neither participants working in general psychiatry identified this as an area of concern, possibly due to greater exposure to and experience with personality disorders. It was interesting to note that many clinicians conflated BPD with an adult manifestation of childhood trauma, or complex PTSD. In fact, recent research has shown that BPD may manifest regardless of whether or not a person has experienced trauma. Current models focus on biological predispositions towards trait impulsivity, and etiological overlap with ADHD (Crowell et al., 2009). Autism clinicians assessing patients with executive dysfunction and deciding whether to attribute these differences to ADHD or BPD could therefore use tools developed to determine whether attachment difficulties lie at the heart of these issues. The Coventry Grid (Flackhill et al., 2017) is a tool geared towards differentiating between autism and attachment difficulties in children, the Coventry Grid for Adults is under development and may prove to be a useful tool for clinicians.

Clinicians disagreed on whether autism and BPD could co-occur, and little research exists having evaluated women for both conditions using gold-standard methods. There was however an agreement between the 4 clinicians who spoke of this, that personality disorder differential diagnoses were gendered. In autistic men, Anti-Social Personality Disorder was seen as possessing some superficial overlap with autism, despite clinicians again highlighting that the intentions behind behaviours were of a qualitatively different nature. This has been discussed in the personality disorder literature, though it does not ultimately seem as if these differential diagnoses are solely the result of clinician bias (attributing similar behaviors to BPD or Anti-Social Personality Disorder depending on the gender of the patient). Rather, it appears that these diagnoses reflect real personality trait differences, such as higher levels of assertiveness found in men, and higher extraversion and anxiety in women (Paris, 2004). Again, refining and hierarchizing the core signs of autism, and how they may present in women as well as men, may be useful in making these differential diagnoses.

The goal of this study was to generate reflection and avenues for refining autistic diagnostic criteria according to clinical expertise. Most qualitative behavioral phenotyping research is limited in geographic scope and range of occupations of clinicians. This was the main strength of our study, which recruited participants from a range of countries and professional contexts. The use of qualitative methodology in this case allowed for in depth exploration of a complex issue, including the subtleties of clinical techniques.

Given that a semi-structured interview schedule was used according to a priori defined issues, participants may have been susceptible to confirmation bias. The involvement of clinicians and research assistants exterior to the research team may have helped to limit this, by ensuring that the interview schedule reflected a clinical reality and that themes were grounded in the data.

## Conclusion

Whilst much research has sought to characterise gender differences in autism presentations through self-reports of autistic women and comparative research on a range of measures, an

emerging field of behavioral phenotyping could complement this work. Based on the idea that those exposed to the most cases of autism have useful insight on what defines this condition, our study demonstrated the use of these techniques in a population susceptible to underdiagnosis and misdiagnosis.

The notion of gender-informed cutoffs must be pursued in the process of screening for autism, as this may rectify underdiagnosis of autistic girls prior to adulthood, where their difficulties may become overlaid with additional adverse life events. Wide exposure to a large number of male and female autism cases (in order to identify core similarities across different presentations), as well as prototypical manifestations of commonly co-occurring or superficially similar conditions, could improve differential diagnosis capabilities in complex cases, such as adult women.

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## Appendices

### I. Table 1. Participant characteristics

<b>Participant ID</b>	<b>Country</b>	<b>Discipline</b>	<b>Type of practice</b>	<b>Years of diagnostic experience</b>	<b>Number of adult women assessed per year for autism</b>
01	Canada	Psychiatry	Specialised/private	25	60
02	France	Psychology	Specialised/private	5	60
03	France	Psychiatry	General*/private	10	25
04	UK	Psychology	Specialised/public	20	30
05	Australia	Psychology	Specialised/private	40	30
06	France	Psychology	Specialised/private	17	30
07	France	Psychiatry	Specialised/private	8	20
08	France	Psychiatry	Specialised/private	7	50
09	USA	Psychology	Specialised/private	12	20
10	UK	SLP**	Specialised/public	15	30
11	UK	Psychology	Specialised/private	25	20
12	UK	Psychology	Specialised/public	10	60
13	Canada	Psychiatry	General*/public	8	20
14	Australia	Psychology	Specialised/private	11	90
15	USA	Psychiatry	Specialised/private	24	20
16	USA	Psychology	Specialised/private	22	30
17	USA	Psychology	Specialised/public	40	10
18	Canada	Psychiatry	Specialised/public	22	40
19	New Zealand	Psychology	Specialised/private	20	25
20	Netherlands	Psychology	Specialised/private	25	30

\*General practitioners see patients for a range of concerns but have specific expertise in autism

\*\*Speech-Language Pathology

## II. Participant Semi-Structured Interview Schedule (English)

General instructions: Unless otherwise specified, the following questions concern your experiences with diagnosing autistic late adolescent and adult women (age 15+)

1. Your discipline
  - Clinical Psychology
  - Psychiatry
  - Other (specify)
  
2. Where do you practice (hospital, private clinic)?
  
3. Years of training and professional experience diagnosing autism (all ages, all genders)
  
4. Approximate number of autism assessments conducted per year (all ages, all genders)
  
5. Of these, approximately what proportion are for adult women?
  
6. In adult women, which beliefs that the patient holds about themselves could make diagnosis more difficult, requiring a second opinion or more advanced evaluation?
  
7. In adult women, which psychological traits and cognitive particularities could make diagnosis more difficult, requiring a second opinion or more advanced evaluation?
  
8. In adult women, which past /differential diagnoses could make diagnosis more difficult, requiring a second opinion or more advanced evaluation?

9. In adult women, which specific autistic traits, when present, best confirm autism, rather than a psychiatric condition?

10. In adult women, which specific autistic traits, when absent, best exclude autism, rather suggesting a psychiatric condition?

11. Which diagnostic/screening instruments best help to bring these traits to light?

12. Which diagnostic/screening instruments do you find unhelpful in bringing these traits to light?

13. During the interview, which topics do you preferentially raise in order to obtain valuable diagnostic information (positive or negative for autism)?

14. Among adult women self or professionally referred to you for an autism diagnostic assessment, what is the proportion of autism diagnoses you finally give?

15. In adult women, do you make use of the “sub-threshold” notion (eg: you belong to the “autism spectrum”, but you are under the threshold for a formal diagnosis)?

16. In adult women, do you preferentially provide a targeted diagnosis of autism or do you generally combine it with a comorbid diagnosis (eg: anxiety, ADHD)?

### III. Protocole de l'entretien semi-dirigé (français)

Directives générales : Sauf indication contraire, les questions suivantes concernent vos expériences en diagnostic d'autisme chez les femmes adultes ou en fin d'adolescence (15 ans et plus).

1. Votre discipline
  - Psychologie
  - Psychiatrie
  - Autre (précisez)
  
2. Où pratiquez-vous (hôpital, clinique privée) ?
  
3. Depuis combien d'années diagnostiquez-vous l'autisme (tous âges, tout sexes) ?
  
4. Nombre d'évaluations diagnostiques d'autisme effectuées par an (tous âges, tout sexes)
  
5. Parmi ces évaluations, quelle proportion sont pour des femmes adultes ?
  
6. Chez les femmes adultes, quelles croiances de la personne sur soi-même peuvent rendre le diagnostic plus difficile, demandant une deuxième opinion ou une évaluation plus poussée ?
  
7. Chez les femmes adultes, quels traits psychologiques et particularités cognitives peuvent rendre le diagnostic plus difficile, demandant une deuxième opinion ou une évaluation plus poussée ?
  
8. Chez les femmes adultes, quels diagnostics antérieurs ou différentiels peuvent rendre le diagnostic plus difficile, demandant une deuxième opinion ou une évaluation plus poussée ?

9. Chez les femmes adultes, quels traits autistiques, si présents, suggèrent de l'autisme, plutôt qu'une condition psychiatrique ?

10. Chez les femmes adultes, quels traits autistiques, si absents, excluent l'autisme, suggérant plutôt une condition psychiatrique ?

11. Quels outils diagnostics/de screening permettent de révéler ces traits au mieux ?

12. Quels outils diagnostics/de screening trouvez-vous non pertinent pour révéler ces traits au mieux ?

13. Lors de l'entretien, quels sujets abordez-vous de manière préférentielle, afin d'obtenir des informations diagnostiques importantes ?

14. Chez les femmes adultes auto ou professionnellement référées pour une évaluation diagnostique d'autisme, quelle est la proportion de diagnostics d'autisme que vous posez finalement ?

15. Chez les femmes adultes, utilisez-vous la notion d'autisme « sous-seuil » (sub-threshold). Ex. Vous faites partie du spectre de l'autisme, mais vous êtes sous le seuil du diagnostic formel. ?

16. Chez les femmes adultes, préférez-vous poser un diagnostic d'autisme ciblé, ou l'associez-vous habituellement à des comorbidités (ex. anxiété, TDAH) ?



**IV. Table 2. A priori issues and themes generated using the Framework Method**

<b>Issues</b>	<b>Themes</b>	<b>Frequency*</b>
Factors of complex assessments	Camouflaging	20
	Sociocultural perceptions of autism	16
	Negative reactions	11
Managing complex assessments	Multiple Tools	15
	Flexible and long	14
	Validate information	18
	Managing negative reactions	10
Signs indicative of autism	Qualitative nature of social difficulties and interests	15
	Discrepancy between intelligence and personal/professional success	10
	Need prompting and instructions	9
	Asymmetry in social relationships	8
	Purpose of diagnosis	6
	Gender identity expression	7
Alternative or cumulative diagnosis	Crisis situations	5
	Trauma	15
	Borderline Personality Disorder	13

\*Total number of participants who identified this theme