# Improving autism identification and support for individuals assigned female at birth: clinical suggestions and research priorities



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Emerging evidence suggests that the higher prevalence of autism in individuals who are assigned male than assigned female at birth results from both biological factors and identification biases. Autistic individuals who are assigned female at birth (AFAB) and those who are gender diverse experience health disparities and clinical inequity, including late or missed diagnosis and inadequate support. In this Viewpoint, an international panel of clinicians, scientists, and community members with lived experiences of autism reviewed the challenges in identifying autism in individuals who are AFAB and proposed clinical and research directions to promote the health, development, and wellbeing of autistic AFAB individuals. The recognition challenges stem from the interplay between cognitive differences and nuanced or different presentations of autism in some AFAB individuals; expectancy, gender-related, and autism-related biases held by clinicians; and social determinants. We recommend that professional development for clinicians be supported by health-care systems, professional societies, and governing bodies to improve equitable access to assessment and earlier identification of autism in AFAB individuals. Autistic AFAB individuals should receive tailored support in education, identity development, health care, and social and professional sense of belonging.

#### Introduction

Autism is a clinical entity (ie, diagnosis) with constantly evolving conceptualisations and definitions, situated at the intersection of the medical and social models of disability.2 The increasing recognition of neurodiversity views autism as an example of neurodivergence (ie, a neurological make-up that functions differently from the normative standards of the neurotypical societies); autistic individuals experience disability from both social (eg, misunderstanding and stigmatisation) and individual (eg, certain cognitive characteristics and medical issues) origins.3 Herein, autism is not only a clinical diagnosis that prompts identification to facilitate access to support, but for some it is also an integral part of one's identity.4 Accordingly, in this Viewpoint we use autism instead of the Diagnostic and Statistical Manual Mental Disorders fifth edition (DSM-5) and International Classification of Diseases eleventh edition (ICD-11) terminology of autism spectrum disorder as it is most inclusive (eg, highlights disability but avoids the disorder connotation attributed to a person).2 We use a blend of identity-first language (eg, an autistic person) and person-first language (eg, a person with autism) on the basis of the considerations of community and family preferences. We use support needs instead of the traditional functioning labels (eg, high-functioning vs low-functioning) as the term support needs more accurately reflects the lived experiences of autistic individuals and their families and is less misleading than the functioning labels.5

We use sex as an umbrella term for biological attributes and gender as an umbrella term for psychological, sociocultural, and contextual attributes. We specify discrete components of sex-related factors (ie, sexed physiology and anatomy, including those related to reproductive health) and gender-related factors (ie, gendered stereotypes about autism in the diagnostic

#### Key messages

- The higher prevalence of autism in individuals who are assigned male than assigned female at birth results from both biological factors and identification biases that are rooted in sociocultural and gendered contexts.
- Health inequity faced by autistic individuals assigned female at birth (AFAB) and their families stems from multiple interacting barriers across societal and interpersonal, workforce and institutional, and research and policy aspects.
- An individual's autism-related presentation can be shaped by gendered contextual influences, and gendered contextual factors can affect the perception and interpretation of an individual's autism-related presentation by others.
- Clinicians should be supported by health-care systems, professional societies, and governing bodies for professional development and training in earlier identification of autism in AFAB individuals, as well as unique care considerations.
- Autistic AFAB individuals should receive tailored support in education, identity development, health care, and social and professional sense of belonging.
- To maximise validity, all domains of autism research should strive for adequate representation of autistic individuals (including those who are AFAB) across different levels of support needs and other intersectional sociodemographics.

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criteria and practice, gender stereotypes and role expectations held by people, and clinicians' own gender stereotypes related to the assessment and care for autistic people) when appropriate, because using the overarching terms of sex or gender in these contexts are not sufficiently accurate. We use assigned sex at birth to describe autistic and non-autistic individuals (ie, assigned female at birth [AFAB] and assigned male at birth [AMAB]) because this construct best captures the populations of concern. Most likely, a person's sex is assigned at birth by their genital anatomy without necessarily including evaluations of other sex-related components (eg, chromosomal and gonadal attributes). This assigned label contributes substantially to how a

#### Panel 1: Sex-related biological factors and autism\*

Biological factors associated with sex might serve as important modifiers that account for the relative malepreponderance of autism prevalence and the heterogeneity in the autism spectrum from neurobiology to behaviour. 6 The lower probability of autism in individuals assigned female at birth (AFAB) might partly stem from sex-related biology. Large-scale genetic studies show autistic AFAB individuals tend to carry more genetic factors associated with autism than do autistic individuals assigned male at birth (AMAB), comprised of both rare and common variants. These findings do not fully explain the increased rates of autism prevalence in AMAB individuals and do not account for the range of the phenotypic variability associated with sex assigned at birth. Nevertheless, current evidence suggests that sex-related biology might contribute to the male-preponderance in prevalence mechanistically via overlapping downstream molecular pathways of sex-differentially expressed genes and autism neurobiology and interacting neuro-immuneendocrine processes early in life.6

Sex-related biological factors also contribute to sexdependent neurobiological features (eg, brain structure and functional organisation) associated with autism and shape autism-related brain development.<sup>11</sup> Differential brain development between autistic AFAB and AMAB children (in comparison to non-autistic AFAB and AMAB children) might further reflect the interplay between sex-related biological determinants and gender-related social contexts, which are experienced differently by AFAB and AMAB children. 12 This interplay further intersects with other sociodemographic contexts to shape behaviours, and subsequently their recognition and the diagnosis of autism by clinicians.<sup>6</sup> Given the paucity of neurobiological research in autistic AFAB individuals and in gender socialisation effects on the development of autistic individuals, it is inadequate to assume what has been found for autistic AMAB individuals can be directly generalised to autistic AFAB individuals. <sup>6,11</sup>

\*For additional reading related to sex-related biological factors and autism see appendix (p 2). person is treated given the gendered contexts in which they live and grow (eg, the gendered expectations to an AFAB child come from the sociocultural expectations of a girl), hence is determined to be most fitting in describing the populations of concern. However, this assigned label might not always be consistent with an autistic person's gender identity. The AFAB population is inclusive of trans-men, non-binary, and other gender-diverse individuals. Although some discussed outcomes are attributable to the entwined effects of sex-related and gender-related factors, others can be specified as attributable to specific components (eg, gender stereotypes).

The conceptualisation of autism as a clinical neurodevelopmental diagnosis comes historically from descriptions of predominantly AMAB children, with considerably fewer AFAB children represented in early clinical reports. This clinical prototype has extensively influenced the operationalisations of autism in the DSM and ICD criteria, and in the creation of standardised diagnostic instruments.7 Later epidemiological studies show, and iteratively reinforce, the stereotypical impression that autism is a so-called male-predominant condition, as shown by the meta-analytical prevalence rates with an overall male-to-female ratio of 4.20:1 (95% CI 3.84-4.60).8 A close examination of study methods and sample sources reveals an intriguing pattern: not only do studies with high-quality methodologies show a lower male-to-female ratio of 3.32:1 (95% CI 2.88-3.84), studies screening the general population show a ratio of 3.25:1 (95% CI 2.93-3.62), both of which differ from clinical samples that show a ratio of 4.56:1 (95% CI 4.10-5.07).8 In unique cohorts of infants with increased likelihood to have autism (ie, those with an older sibling diagnosed with autism), the male-to-female ratio for those meeting autism diagnostic criteria at 3 years of age is 3.18:1.9 When autistic features are adjusted for age-related and sexrelated non-invariance, data-driven latent trajectory subgrouping shows an almost 1:1 male-to-female ratio in the subgroups with heightened autistic features, and AFAB siblings with elevated social concerns showed milder features than AMAB siblings in this subgroup: nevertheless, more AMAB than AFAB siblings receive a clinical autism diagnosis (3.3:1).10 These data suggest that there is an under-recognition and diagnostic inequity faced by AFAB individuals when it comes to being identified as autistic, partly contributing to the malepredominance in autism prevalence (for biological implications<sup>6</sup> see panel 1). This inequity might have resulted in far fewer autistic AFAB individuals being included in research and thus less knowledge of how autism presents and can be experienced differently in AFAB individuals.<sup>11,13</sup> This discrepancy in understanding can, in turn, contribute to obstacles in developing evidence-based support, appropriate understanding, and timely identification of autism for this group. Accordingly,

See Online for appendix

research findings (including biological, social, or clinical) from samples of predominantly AMAB autistic individuals and their clinical translations cannot be assumed to be generalisable to AFAB individuals diagnosed with autism (panel 1). Furthermore, there are increasing reports of greater sexual diversity and gender identity diversity in autistic people across ages, especially in AFAB individuals, highlighting the need to understand intersectionality for tailored support. More inclusive research designs are required to offer sexequitable and gender-equitable knowledge and practice implications for autistic people across the lifespan, especially considering the impact of sex-related biology, gender identity, and gender socialisation.

By integrating diverse international, cultural, personal, and family perspectives, we aimed to identify factors contributing to this inequity, make practical recommendations to facilitate earlier identification of autism to improve the health and wellbeing of autistic AFAB individuals across the lifespan, and to identify research priorities that facilitate the enactment of our recommendations. To achieve this goal, the Autism Science Foundation convened regular monthly meetings accompanied by working group discussions throughout 2021-22 with an international panel of clinicians (paediatricians, clinical psychologists, and psychiatrists), scientists (autistic and non-autistic researchers of autism and developmental science), and community members with lived expertise (autistic AFAB individuals and women from different racial and ethnic groups who have been diagnosed with autism at different life stages, and family members of autistic AFAB individuals) to discuss the challenges in identifying autism in AFAB individuals and clinical improvement opportunities, with the broader goal of promoting health, development, and quality of life. A research agenda was also developed through a multi-step, iterative, collaborative process (appendix p 2).

## Clinical inequity and health disparities faced by autistic AFAB individuals and their families

The health inequity faced by autistic AFAB individuals and their families stems from multiple levels of barriers (figure; appendix pp 3-4). Even with improved autism awareness and capacities to diagnose autism by 18 months of age, 17 the age distribution of first autism diagnosis remains later in AFAB compared with AMAB individuals across high-income countries (HICs) and low-income and middle-income countries (LMICs).18-24 The delay in receiving a correct diagnosis, something that many AFAB individuals face, contributes to poor outcomes, including self-criticism and low self-esteem, persistent feelings of isolation in institutional environments, poorer educational outcomes, delayed access to appropriate support, and increased likelihood of experiencing harm or trauma (including abuse, discrimination, social isolation and rejection, and sexual assault).25-27 These circumstances increase the likelihood

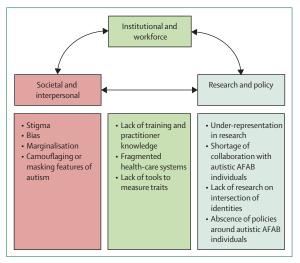


Figure: Health inequity faced by autistic AFAB individuals and their families. Further information can be found in the appendix (pp 3-4).

of mental health difficulties.<sup>28</sup> The situation is compounded by potential misdiagnosis due to diagnostic overshadowing or misinterpretation of co-occurring conditions (eg, anxiety disorders, attention-deficit hyperactivity disorder [ADHD], eating disorders).<sup>29-32</sup> Families can also be uniquely affected by a late diagnosis of their AFAB child, causing a tremendous amount of guilt or regret on behalf of the parents for feeling that they were responsible for the oversight of earlier signs, or were to blame for the challenges their loved one faced growing up.<sup>33</sup>

AFAB individuals diagnosed with autism also have pronounced health challenges,<sup>34</sup> some of which relate to underlying biological factors (eg, genetic and neurological, and those related to sexed physiology and anatomy), such as epilepsy, endocrine and reproductive health conditions,<sup>35,36</sup> and premature mortality.<sup>37</sup> Missed or late diagnosis of autism, and co-occurring mental health challenges,<sup>28</sup> might further aggravate these health disparities. Suicide is also a cause of premature mortality, especially in autistic AFAB individuals.<sup>38,39</sup>

Social exclusion further compounds the disparities faced by autistic AFAB individuals. In autistic children and adolescents with intellectual disabilities, AFAB individuals experienced more social exclusion than their AMAB peers, even after accounting for age, level of intellectual disability, and support needs.<sup>40</sup> In a longitudinal study with 73 adults, although 31% of autistic AMAB adults were consistently engaged in postsecondary education or in competitive employment, none of the autistic AFAB adults was consistently engaged in these settings.41 Autistic AFAB adults with and without children were more likely to indicate that they were withdrawing from the labour market, 42 indicating possible double vulnerability in the workplace due to both gender-related factors (eg, gender stereotypes and gender role expectations) and autistic status. Even for AFAB individuals who are diagnosed and For more on the **Autism Science**Foundation see https://
autismsciencefoundation.org

#### Panel 2: Intersectionality experienced by autistic AFAB individuals\*

The heightened sexual diversity and gender identity diversity in autistic individuals, especially those assigned female at birth (AFAB), emphasises the importance of clinicians' understanding of this intersectionality to meet the autistic person's unique support needs. <sup>14,15</sup> This includes timely recognition of autism in gender and sexually diverse individuals; knowledge of social identity development; psychosocial–environmental support for sexual wellbeing, gender wellbeing, and sexual and gender development considering the autistic ways of being; and support for navigating care, especially when it involves complex decision making and exploration (eg, gender-affirming care). <sup>15</sup>

Autistic children of colour, especially AFAB individuals, living in North America and Europe are frequently diagnosed later and less often than their white peers. <sup>46</sup> The reasons might include systemic barriers to health care (eg, structural racism), differences in health literacy, and racial-ethnic biases of the providers in interpreting and understanding caregiver concerns. <sup>47,48</sup> For example, Black parents' concerns might be viewed as neutral, even when the information presented is a cause for alarm. Concerns can be outright dismissed, leading to delays in the referral process, restricted access to autism professionals, and low-quality care. Cultural differences in health-care paradigms and, for some, the stigma around accessing mental health services (including autism support) can exacerbate problems in obtaining a diagnosis. Insufficient representation of providers with diverse ethnic, cultural, and language backgrounds to adequately serve autistic individuals and their families aggravates these barriers.

Culture affects how the behaviours of autistic people are shaped and how autism features are perceived, which both intersect with gendered contexts. For example, sustained eye contact is not universally perceived as symbolic of connection and positive interaction; in various cultures, mutual eye contact could be considered a sign of disrespect, defiance, and potentially aggression, and is therefore discouraged. Call and response patterns are also a part of culture; what is labelled as echolalic or stereotyped speech could serve various functions and be perceived differently across cultures. As playing independently and entertaining oneself is a sign of maturity in some communities (eg, several West African ethnic groups), differences in perceived social–emotional reciprocity or interaction are accepted. Some behaviours considered rigid, restricted, or deficits in some cultures are not problematic in others; in some cultures (eg, some West African and Latinx cultures), wanting books or toys organised by height or colour is not seen as atypical, but represents the virtue of orderliness. Sensory-seeking autistic children who live in a culture encouraging movements might be missed because their environment suits their sensory needs. Some aspects of culture can accommodate the needs, but also might mask the child's underlying differences. Therefore, the use of diagnostic tools that narrowly define differences could be inappropriate.

The autistic tendency for direct and clear communication is perceived differently according to gender. Given that in the general population, individuals assigned male at birth (AMAB) are more likely to be perceived as showing leadership potential than AFAB individuals, autistic AFAB individuals might be seen as bossy and the intersection of autism and gender hinders their wellbeing and career progress. Adding racial-ethnic intersectionality, Westerners might be even more judgemental of autistic AFAB individuals who are Black, Indigenous, people of colour, and visible minorities (eg, judging them as 'tactless', 'rude', 'bossy', or 'controlling').

\*For additional reading related to intersectionality and autism see appendix (p 2).

have access to services, current models of support have much room to improve to address social needs, sexual vulnerability, and health challenges.<sup>43,44</sup> Although heterogeneous and different levels of autism characteristics, disabilities, and support needs exist, these and other disparities tend to lead to a cascade of poorer outcomes especially for AFAB individuals, such as mental health challenges, poorer physical health, and social-emotional difficulties.<sup>45</sup>

Another crucial factor that thwarts progress toward supporting the health and wellbeing of this population is a scarcity of research. Research for AFAB individuals diagnosed with autism and their key intersecting groups such as gender and sexually diverse individuals; families of diverse racial, ethnic, and linguistic backgrounds; people living in LMICs; and those with high support needs (such as being non-speaking or with intellectual disability)—is far from complete, due to their under-representation in research and inadequate a priori consideration of their unique experiences and intersectionality in research design (panel 2).6,11 For example, the variability of gendered sociocultural effects on autistic AFAB, AMAB, and intersex individuals' development and wellbeing associated with their different gender identities is essentially unknown. The failure to over-sample an under-represented group impedes the capacity of professionals and service sectors to promote the health and wellbeing for all autistic people through policy and practice.

## Intertwining individual and contextual factors related to timely autism identification in AFAB individuals

Research suggests that the under-recognition of autism in AFAB individuals might come from the interplay of individual (eg, cognitive abilities) and contextual factors (eg, gendered expectations, clinician experience), 49 modulated by development, 50 underlying biology, 51 and social determinants, including race and ethnicity. 46,52

### Individual presentation can be shaped by contextual influence

On average, AFAB individuals who have a clinical autism diagnosis tend to have similar social-communication scores compared with autistic AMAB individuals, but lower restricted and repetitive behaviour scores on standardised measures of autism features.53 Earlydiagnosed AFAB individuals are more likely to have developmental delay (eg, speech or motor delay), intellectual disability, or co-occurring emotionalbehavioural challenges than AMAB individuals;12,54-56 however, such instances are not seen in autistic children who are identified through increased-likelihood (eg, sibling) cohorts, where ascertainment is not dependent on clinical referral.<sup>9,57</sup> Conversely, individuals with advanced verbal abilities tend to receive autism diagnoses at a later age, which is more evident in AFAB than AMAB individuals. 19,21,58 AFAB and AMAB individuals might meet the autism diagnostic criteria in somewhat different ways.<sup>59</sup> Some autistic AFAB individuals show more culturally based, gender-stereotypical and less object-focused interests (eg, more likely to focus on

people, animals, or characters, for which the interest is expressed through social activities) than do AMAB individuals,60-62 which could be missed especially if clinicians rely heavily on standardised screening questionnaires rather than full assessments. Additionally, some autistic people, especially AFAB individuals, show nuanced social-communication differences that might not be well captured by standardised instruments or observation,63 including enhanced social attention and motivation, gender-stereotypical symbolic and imaginary play, use of non-verbal communication, or other masking (eg, suppressing mannerisms) and compensation (eg, scripting conversations) skills rehearsed across development<sup>49</sup> as a way of social coping and, in some instances, to minimise manifestations of externallyobserved autistic traits. 64,65 Social and gendered norms about expected behaviours could dictate how AFAB children play and how they behave alongside peers,66 and such experiences might scaffold them to assimilate into their environment. 67 Sex-related individual characteristics (eg, attentional focus), gender-related contextual factors (eg, socialisation experiences), and their interplay (eg, interpersonal behaviour resulting from social attention modulated by gender socialisation) could explain why longitudinal studies with children diagnosed with autism in early childhood tend to find that a higher proportion of AFAB individuals is observed in the subgroup with declining observable autistic behavioural presentations (as measured by the Autism Diagnostic Observation Schedule) over time. 68,69 Meanwhile, gender-related contextual demands (eg, gender stereotypes, gender relations, gender role expectations) might interact with individual characteristics to pose great challenges during adolescence, especially for AFAB individuals. 53,70 This combination could partly explain the increased referral of AFAB individuals for autism diagnoses in adolescence and adulthood.71,72 These complexities highlight how the identification of autism is influenced by the interplay between individual characteristics (eg, verbal ability, focused interest, social attention), contextual influence on individual presentation, and external perceptions or expectations given the sociocultural and gendered contexts, reflecting the need for a comprehensive and nuanced approach to interpreting assessment data. 49,73,74

## Contextual factors affect the perception and interpretation of individual presentation

Given comparable clinician-rated outward autistic behaviours, autistic AFAB children tend to have greater parent-observed autistic traits and more adaptive functioning challenges than do AMAB children;<sup>75</sup> this implies that autistic AFAB children might be visible to clinicians only when they experience more challenges than autistic AMAB children.<sup>55</sup> The prevailing stereotypical impression of autism, which is substantially gendered (eg, *The Rain Man* or *The Good Doctor* 

stereotypes in popular media, which predominantly portray autistic people as white males with a specific, overt presentation of social-communication differences as well as savant skills and strengths in maths and science), might lead clinicians to dismiss (or not consider) a potential autism diagnosis in AFAB individuals.25 Contextual demands that drive impression management (ie, one's tendency to show favourable impressions of oneself in front of others during social interactions) or survival instincts in response to discrimination or social victimisation could also prompt some autistic people to hide autism-related differences:65 this demand could be more substantial for autistic AFAB individuals owing to the pressure from gendered contexts.64 Such efforts might lead to the unnoticed presence of autism in AFAB individuals until the occurrence of so-called unmasking or a mental health crisis, thereby making the accurate identification of autism more challenging.74

Health disparities are influenced, in part, by the biases of clinicians.76 Implicit and explicit gender stereotypes are prevalent, and clinicians can be vulnerable to such stereotypes—especially in the absence of adequate training and education in this area.77 The expectancy bias and gender stereotypes held by referral sources and clinicians influence how autistic characteristics are perceived and how likely it is that autism will be considered, 59,66,78 intersecting with sociocultural contexts and clinicians' implicit and explicit racial biases related to autism. 47,48 Multiple intersecting contextual factors thus interact with individual presentations to influence clinicians' confidence of diagnosing autism. The exact patterns of diagnostic biases or overshadowing differ by country, by how the diagnostic data are ascertained, 56,79 and by the features observed during evaluations.80

A few experimental studies have begun to show how gendered contextual factors influence clinical judgement and decision making of practitioners. Using case vignettes with typically-female names reduces UK educators' consideration about a possible autism diagnosis than when using typically-male names when the vignettes include what might be perceived as subtle autism presentations. On the other hand, when typically-female names are used in case vignettes, diagnosticians in Australia are more likely to assign greater perceived levels of autism-associated difficulties than when typically-male names are used; these same diagnosticians report feeling less confident in assessing for autism in girls and women than boys and men. Example 12.

#### Recommendations for clinical practice

Earlier identification, equitable access to assessment, accurate diagnosis, appropriate understanding of the autistic person, and tailored support result in more positive outcomes throughout life and facilitate needed health care, adaptive identity development, and illness

## Panel 3: Lived experiences of the identification and support needs of autistic individuals assigned female at birth (AFAB)\*

- "My daughter did not line up balls or spin the wheels of toy trucks, which is what the diagnostician asked me about."
- "In part-time daycare, my daughter didn't show the typical fear response upon drop
  off. This was not concerning to anyone; they actually perceived her as more socialised."
- "My daughter liked to stim with her hair, but because it was socially acceptable to twirl your hair, no one thought that it was odd."
- "I was friends with all the other girls in my class until about 6th grade. By then, they
  were interested in boys, makeup, Taylor Swift, and sports. They didn't care about
  Japanese anime and I had nothing in common with them, and I felt even more
  awkward. They started calling me weird. It hurt my feelings."
- "I can see a little bit of anxiety and OCD in my daughter, but I am being told it is part of the autism."
- "[As an autistic child] I completely cut off my ponytail once on the bus en route to
  school one day using my safety scissors. That day, the feeling of hair brushing against
  my shoulders and back, which I usually liked, was so overwhelming and painful; the
  only solution I could think of was to get it off me that very moment in whatever way I
  could. This was perceived as defiant behaviour rather than a desperate attempt for
  sensory relief."
- "When my daughter was placed in a vocational programme, they put her in programmes with all boys in things she was not interested in. They involved lots of manual labour, copying, and office work. Nobody asked what she wanted to do."
- "I've considered homeschooling my child because there are less stressors and fewer distractions. Plus, there are no concerns for bullies or getting picked on. Having a flexible schedule might also open a window for therapies for functional social interaction."
- "Because I didn't understand nor comply with social nuances I was perceived as disrespectful."
- "It seemed like everyone around me had some type of handbook to life that I didn't.
   Everything was so hard and though I pretended to be the same as everyone else, I was
   overcome by constant anxiety. I practiced every day for hours so I could copy the
   words and mannerisms of my peers instead of speaking and moving the way I did
   because somehow it wasn't right."
- "My daughter is unable to tell me what is going on with her body, and (when I query her) she says, 'Fine, fine, fine'. It is a constant struggle to understand her challenges with menstruation, anxiety, and even bullying."
- "Even in adulthood, I still have difficulties with reaching out for medical help. If
  everything hurts (eg, stomach pain, muscle tension, headaches, sensory sensitivities
  to sounds, smells, lights), how do you know when something is really wrong? We learn
  not to ask for help until the pain is unbearable and we cannot cope."

\*Excerpts were derived from firsthand experiences shared by autistic AFAB individuals and parents of autistic AFAB individuals, with the valuable contribution of one autistic AFAB parent who also had an autistic AFAB child. They serve as illustrative examples that emphasise the specific educational, training, and awareness needs of clinicians, caregivers, educators, and service providers. See the appendix (pp 5–16) for a full version. AFAB=assigned female at birth. OCD=obsessive compulsive disorder.

prevention (panel 3).<sup>83</sup> Addressing contextual biases is crucial for timely identification and support for all AFAB individuals. Some AFAB individuals are not diagnosed with autism until late childhood, adolescence, or adulthood, <sup>23,84</sup> or diagnosed with other neurodevelopmental or psychiatric conditions first (eg, language disorders or ADHD in childhood, mood disorders, eating disorders, personality disorders in adolescence and adulthood, or anxiety disorders across ages). <sup>29–32,85</sup> To improve diagnostic accuracy (ie, minimising

underdiagnosis and overdiagnosis of autism) and properly consider differential diagnosis, the assessment should integrate multiple data sources on developmental history and current presentation and functioning (rather than solely relying on scores of specific instruments), and the diagnostic formulation should reasonably explain the person's and family's life journey while accounting for the effect of other neurodevelopmental and psychiatric conditions. 49,86,87 Thus, training for clinicians to adopt developmental and sociocultural lenses for assessment and differential diagnosis, and methods for reducing systems-level inequity that do not sacrifice quality of care, are essential. Health-care systems, governing bodies, and relevant professional societies should support clinicians to receive training (eg, via developing training guidance and dedicating funding support) in multidisciplinary team environments, as well as work with autistic AFAB individuals (and their families) with varying clinical presentations and needs, to enhance awareness and combat their own biases about autism, gendered stereotypes of autism, and gender stereotypes more broadly; it is also important to analyse how sociocultural factors shape an autistic person's behavioural development and life experiences, and to consider these factors in diagnostic assessments. A participatory framework that engages autistic AFAB individuals and their families is essential in these capacity-building initiatives and advocacy for systemslevel improvement of access to care, especially for those seeking assessments in adolescence and adulthood (appendix p 2). Recommendations for six key areas can be found in panel 4 and the appendix (pp 5–16). These areas, including early identification, clinician training, educational support, identity development, health care, and fostering a safe and enriching sense of belonging, span the lifespan from infancy to adulthood and encompass various forms of support, including social and medical assistance.

AFAB individuals who are diagnosed early in life tend to present with prototypical autistic characteristics (ie, pronounced features such as minimal eye contact or frequent motor mannerisms) or evident developmental delays early on.54 Here, the likelihood and potential impact of a genetic diagnosis is increased,88 often necessitating specialised assessment and health supports across the lifespan. It is crucial that clinicians understand how autism manifests differently across developmental levels and stages, and the behavioural similarities and differences between autism and other conditions; when confirming an autism diagnosis, they must understand the effects of developmental, language, and cognitive variability on the emergence and presentation of autistic features, considering the sociocultural contexts. In some scenarios, the presence of high verbal abilities or global developmental delay can obscure overt manifestations of autism characteristics in the early childhood years. These traits might only become readily apparent in the context

## Panel 4: Areas of concern and recommendations for enhancing clinical care for autistic individuals assigned female at birth (AFAB)

## Earlier identification and accurate diagnosis of autism in AFAB individuals

- Be aware of common diagnostic biases towards autistic AFAB individuals, especially the implicit and explicit gender stereotypes and stereotypes about autism
- Be aware of common co-occurring conditions, diagnoses, and misdiagnoses (eg, multiple anxiety disorders, attention-deficit/hyperactivity disorder, eating disorders, personality disorders)
- Assessment for social-communication and behavioural development and needs of AFAB individuals should consider the appropriate reference groups based on sexrelated developmental trajectories, gendered contexts, and intellectual and language capabilities
- Be aware of the wide variety of presentations and experiences of AFAB individuals and families
- Develop a better understanding of how culture shapes individual behaviour and the perception of such, and how structural racism, poverty, and other inequities intersect with gender to influence the recognition and care for autistic people
- Autism should not be ruled out based on a one-time behavioural observation

#### Clinician training and professional development

- Regular crosstalk and collaboration across disciplines
- Enhance training for first-time diagnostic assessment and support, particularly regarding common co-occurring or prior diagnoses (and misdiagnoses)
- Work to combat implicit and explicit biases surrounding autism (eg, lack of empathy, theory of mind deficits), gendered stereotypes about autism, and clinicians' own gender stereotypes
- Follow a participatory framework to learn about wellbeing priorities of autistic AFAB individuals and their families
- Keep up to date with the literature on assessment tools and how they function in different populations

#### **Educational support**

- A timely, tailored, well-documented, and regularly updated accommodation and educational plan throughout the educational journey
- A safe peer-environment considering gendered contextual factors
- Support autistic AFAB individuals and their guardians (when applicable) to make decisions that are safe and supportive to minimise trauma and victimisation
- Advocacy training and psychoeducation about resources and components for good care plans should be available to educators and administrators

#### Identity development

- Support the autistic individual to foster their acceptance of being autistic and a positive sense of self
- The social-communication profiles of autistic AFAB individuals and the contexts they experience can be leveraged early to support social development and learning opportunities

#### Health-care and medical issues

- In addition to physical and mental health challenges, special considerations should be given to gynaecological and obstetric needs
- Understand the unique autistic person's comfort zone and to actively seek consent and empower self-advocacy
- Ensure medical support that includes continuity of care within the primary care system, as well as access to specialised health services as needed

## Safe and enriching social and professional sense of belonging

- Facilitate the development of autistic-to-autistic peer support groups and related services and resources
- Family wellbeing is fundamental—assess and respond to needs in this area

of greater social demands and such variation by context and developmental stage could complicate the evaluation process. 49,86,87 After the assessment, respectful and honest communication with the autistic AFAB person and their family about the nature of an individual's difficulties, including use of precise nomenclature, is essential. 89 Across the spectra of abilities and autistic characteristics, it is imperative that the clinician obtains a complete picture of the autistic individual's strengths and challenges, and to support them in cultivating health-related self-advocacy abilities. It is integral to help individuals and families to understand the diagnosis in a strengths-based manner that recognises their full potential, hopes, and aspirations, and does not focus solely on the challenges and uncertainties of the future. 90

A socioecological approach informs required support, recognises behaviours that might be self-regulating or desired, and identifies when social and sensory environmental changes are necessary; this environmental adjustment is synergistic to, and can sometimes be more important than, didactic social teaching targeted at the autistic person. Self-advocacy then becomes essential (in the absence of a guardian) for receiving the appropriate accommodations and for increasing awareness of the need for environmental adjustments. Linicians have a unique role in supporting autistic individuals' identity development, which is essential as a stronger sense of autistic social identity might be associated with enhanced self-esteem and improved mental health; 33,94 more research is needed about the role

of autistic personal identity and how it relates to selfesteem and wellbeing. Clinicians should attend to these considerations (many of which are applicable broadly to all autistic individuals) and how they intersect with gender and gendered experiences of the AFAB individual. Establishing preferred communication styles upfront is an important factor in building a trusting, collaborative relationship between the clinician, the client, and the family, leading to better outcomes. Clinicians should recognise the range of communication differences and

#### Panel 5: Priority research areas with a particular focus on autistic individuals assigned female at birth (AFAB)

#### Content areas

Contextual factor-related barriers to the identification of autism

- How gender stereotypes and gendered contexts in different cultures affect individual development
- How family and contextual factors contribute to barriers to diagnosis and support for autistic AFAB individuals
- How contextual factors contribute to ascertainment biases

Heterogeneity in presentation and support needs

- Adapted support to address the unique needs of autistic individuals who are AFAB (eg, navigating relational aggression, minimising sexual victimisation, responding to sexism)
- Diagnostic stability and timing (including differences between those who are diagnosed early vs late)
- Better description of autism phenotypes through the lifespan (including aging)
- Characteristics of self-identification (eg, self-diagnosis) in the absence of an official clinical diagnosis
- Identifying risk factors and treatments for co-occurring neurodevelopmental and mental health conditions (eg, attention-deficit/hyperactivity disorder, trauma, anxiety, and depression)

Intersectionality

- Experiences of individuals who are both autistic and caregivers
- Intersections among gender identity diversity, sexual diversity, gender-related contextual factors, and sex-related biological factors
- Focusing on autistic AFAB individuals with multiple marginalised identities (eg, Black; Indigenous; people of colour and visible minorities; two-spirit, lesbian, gay, bisexual, transgender, queer, intersex, asexual, pansexual, and more [2SLGBTQIAP+]; low socioeconomic status; other disabilities)
- Cultural influences interacting with gender-related factors on autistic behaviours and the recognition of such

Quality-of-life-focused diagnosis and assessment

- Advancing evidence supporting accurate and meaningful diagnostic measures and practices, and incorporating sex and gender considerations into professional training about assessment and diagnosis
- Identification of genetic, neurological, and other mechanisms that can inform efforts to improve quality of life and promote resilience

Improving institutional supports and services

 Care coordination between paediatrics, clinical genetics, clinical psychology, obstetrics and gynaecology, behavioural

- health, endocrinology, neurology, psychiatry, primary care, and other specialists such as dental and optometry providers, occupational therapists, and speech and language therapists
- Quality improvement approaches for both general primary care practices and specialty care for 2SLGBTQIAP+ populations (eg, creating and testing inclusive care models)
- Developing, implementing, and evaluating educational supports across the life course for autistic AFAB individuals

Research to identify the underlying mechanisms of the presentation of autism over the lifespan in individuals who are AFAB

- Multilevel data collection to understand sex-specific aspects of development, such as effects of pubertal status on brain development
- Interdisciplinary, genetic, and neuroscience studies with sufficient numbers of AFAB individuals to identify sex-specific biomarkers, predictors of outcomes, and support needs

#### Methodological areas

Community-based participatory research

- Understanding the needs, experiences, and priorities of autistic AFAB individuals and their families
- Implementation and evaluation of recommendations from grassroots collaborative initiatives, for example in the USA, the Autistic Self Advocacy Network, the Academic-Autistic Spectrum Partnership in Research and Education, and the Autistic Women & Nonbinary Network
- Data collection materials developed with autistic AFAB individuals and their families

Population-level data collection across intellectual abilities and levels of support needs

- Large-scale, representative survey research
- · Longitudinal research designs

Life-course oriented research

 Longitudinal studies to track needs across the lifespan, particularly at key developmental transitions (eg, transition into school, puberty, emerging adulthood, older adulthood)

Data collection across systems

- Data collection across multiple systems and sectors that represent contexts of both opportunity and risk, including education, work, vocational settings, health-care settings, social and interpersonal contexts, and family contexts
- International epidemiological studies that examine sex and gender effects from a developmental perspective, to aid in disentangling sex-related biological and gender-related sociocultural impacts

For more on the **Autistic Self Advocacy Network** see https://
autisticadvocacy.org

For more on the Academic-Autistic Spectrum Partnership in Research and Education see https://autismandhealth.org

For more on the Autistic Women & Nonbinary Network see https://awnnetwork.org

preferences in autistic people and support the use of valid strategies to ensure accurate, meaningful communication. It will also ensure the clinician can appropriately promote positive identity development both socially and emotionally-for the diagnosed AFAB individual. Recognising that autistic individuals and their family might have different communication styles and preferences, clinicians should be prepared and informed to communicate with both parties in tailored and respectful ways.2 One way to begin is simply by asking, "What is your most comfortable way to talk about autism? Do vou prefer person-first (a 'person with autism') or identity-first language (an 'autistic person') or do you have a different preference (ie, both or neither)". In many English-speaking HICs, caregivers of younger, non-speaking, or minimally verbal individuals might frequently prefer person-first language when referring to their children, whereas autistic AFAB individuals who self-advocate for their needs often embrace autism as an intrinsic part of their identity and tend to use identityfirst language;4 however, this pattern varies in non-English speaking HICs.95 Context is important when considering language; a singular dictionary is inadequate, and it can change over time. Although some individuals prefer identity-first language, person-first language originated from people with disabilities and both choices should be respected as valid options. This is parallel to asking about (rather than assuming) a person's honorific and gender pronouns, especially considering the greater gender diversity in autistic individuals across the lifespan. 6,14 How language preferences vary in LMICs and communities using other languages or with various sociocultural backgrounds remains under-researched and insufficiently understood.

Because autism is diagnosed more frequently in AMAB individuals, many clinicians have limited experience with care planning for autistic AFAB individuals. Special attention is needed to ensure that support goals are tailored to promoting developmentally appropriate and gender-informed social opportunities,96 coordinated with other systems (eg, school). In our collective experiences, many autistic AFAB individuals and their families report feeling out of place in social or support groups that are primarily designed with autistic AMAB individuals in mind, with peers who are at different developmental levels or, in the case of mental health support, not tailored to the needs of autistic people nor accounting for the intersectionality of gender, sexuality, and autism. 43,97 Providers also need to understand that the social context is heavily affected by gender (eg. gendered structures and expectations) and its intersectionality (eg, with race, ethnicity, and culture),98 and hence AFAB individuals have unique experiences. For instance, social interactions between girls, autistic or non-autistic, tend to involve more shared conversations and attention to social groups than in boys, with girls engaging in more relational aggression than boys. 96 Thus, there are more opportunities for social challenges or breakdowns in communication for autistic AFAB individuals, resulting in greater social gaps, isolation, and stressors than for autistic AMAB individuals. Social contexts, including the roles that sex and gender play, change across development. Clinicians must understand how expectations for social interaction, opportunities, and challenges change over time, and how these changes might uniquely affect the wellbeing of autistic AFAB individuals. 53,70,97 Such changes involve the pressure of gender roles and the risk of sexual victimisation,25 and physiological and psychological issues related to reproductive stages (eg, menstruation, pregnancy, and menopause).99 Accordingly, most autistic individuals will benefit from periodic re-evaluations and ongoing clinical care to update and identify relevant care goals and strategies. Autistic AFAB individuals can also have substantial mental health and physical health challenges.<sup>28,35,37</sup> Regular attention to wellbeing topics with the incorporation of women's health, sexual and reproductive health, and gender-related care needs is essential.16,35

## Moving forwards: a research agenda to address inequity faced by autistic AFAB individuals

New research focusing on mitigating barriers in social and interpersonal contexts, education, or health-care settings, and within broader systemic contexts that dictate research and policy is one avenue towards achieving greater health equity for autistic AFAB individuals. To maximise validity, all domains of autism research should strive for adequate representation of autistic individuals (including those who are AFAB) across different levels of support needs and other intersectional sociodemographics. Such representation corresponds with major funding agency policies currently mandated in some HICs. <sup>100</sup> In the USA, for example, evaluating autistic women and girls is a crosscutting goal that spans all seven objectives of the Interagency Autism Coordinating Committee.

#### Search strategy and selection criteria

The literature search was based on major topic areas identified through iterative discussions among panel members, rather than a single systematic literature review. Searches were conducted iteratively throughout the project period (Jan 1, 2021–Dec 31, 2022) with PubMed and Google Scholar, using the search terms "autism", "sex", "gender", "female", "girls", "women" in combination with terms pertaining to identified topic areas: "prevalence", "diagnosis", "bias", "health", "service", "intervention", "disparity", "barriers", "inequity", "race", "ethnicity", and "intersectionality". Panel members also recommended literature to be included based on their expertise, which were synthesised into this Viewpoint.

For more on the Interagency Autism Coordinating Committee see https://iacc.hhs. gov/publications/strategicplan/2019 We propose a research agenda (panel 5) that includes general and specific priority research needs, spanning content and methodological areas, to address barriers to equity. This agenda is not meant to be exhaustive, rather to highlight priority areas moving forward. We are hopeful that ongoing and future research in these areas will bring clinical and real-life impact to ensure a fulfilling and empowered life for autistic AFAB individuals and their families across diverse populations.

#### Contributors

SG, M-CL, and AH led regular discussions of the authors. M-CL drafted the manuscript and integrated author input for revisions. All other authors contributed equally to contributing ideas, writing sections, and editing different versions. HMB, MGO, AH, EH, AK, and DM are authors who are on the autism spectrum or a family member of an autistic person. This Viewpoint is jointly written by all authors to offer diverse perspectives and consensual recommendations.

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M-CL has received research funding support from the Canadian Institutes of Health Research Sex and Gender Science Chair (GSB 171373), and editorial honorarium from SAGE Publications. SB has received royalties from Western Psychological Services for sales of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), consulting fees from Janssen, and honoraria for trainings on best diagnostic practices for autism, as well as trainings on use of the ADOS-2 and the Autism Diagnostic Interview-Revised (ADI-R). MGO is supported by the Ford Foundation and Next for Autism. AH is an employee of the Autism Science Foundation, has received honoraria for serving as a reviewer for the US Centers for Disease Control and Prevention, has received travel support from Emory University, serves as the Chair of a Data Safety Monitoring Board for a project at Drexel University, and is a member of both the Phelan McDermid Syndrome Foundation and the Interagency Autism Coordinating council (both unpaid). CH has received research funding support from the US National Institute of Child and Human Development, US National Center for Advancing Translational Sciences, the Eagles Autism Foundation, the Autism Science Foundation, and the Organization for Autism Research, and has received honoraria for serving as a reviewer for the US National Institutes of Health and US Department of Defense. CWN has received research funding support from the US National Institute of Mental Health (R01MH127046). ABR has received research funding support from the US National Institute of Mental Health (R01MH10028-12). CS has received royalties from Pearson Assessments for the Vineland Adaptive Behavior Scales, Third Edition and Wiley for two books related to autism and adaptive behaviour. KS has received research funding support from the US National Institutes of Health, Department of Defense, Missouri Department of Mental Health, Autism Speaks, and Cognoa; grants or contracts from the American Board of Pediatrics, University of Idaho, and University of New Mexico; consulting fees from Autism Navigator and Quadrant Biosciences; honoraria from WebMD/Medscape; payment for expert testimony from Missouri Board of Healing Arts; and has a leadership or fiduciary role in the American Academy of Pediatrics. LZ has received funding support from the Stollery Children's Hospital Foundation Chair in Autism. All other authors declare no competing interests.

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