

Living Guideline Supplementary Paper

**Aotearoa New Zealand Autism Guideline:**

Supplementary Paper on sex/gender differences

in the presentation of autistic characteristics

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**Contributorship and independence**

*Marita Broadstock* (INSiGHT Research) conducted the umbrella review of systematic reviews, and prepared this Supplementary Paper. She manages the Autism/Takiwātanga Living Guideline programme; a process for ensuring the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (3rd edition, 2022) [1] remains up to date.

An advisory panel known as the *Living Guideline Group* (LGG) considered the body of evidence presented in this paper in revising and grading Recommendations and Good Practice Points to update the Guideline. Their decisions are reported in [**Part 3**](#Part3).

Contributors have no financial or other perceived or real conflicts of interest pertaining to the reviewed material.

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**Statement of intent**

INSIGHT Research produces evidence-based best practice guidelines and systematic reviews to assist affected individuals, families/whānau, clinicians, educators, and policy-makers make decisions about the best supports available. The evidence is developed from systematic reviews of international literature and placed within an Aotearoa New Zealand context. Guidelines, including Supplementary Papers, are not intended to replace a clinical specialist/practitioner’s judgement in individual circumstances.

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This Supplementary Paper updates evidence for the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (2022) [1] and should be read in the context of the Guideline and previous Supplementary Papers [1-15]

Currency review date: 2029

Table of Contents

Executive Summary 1

Scope 1

Method 1

Umbrella review findings 1

Conclusions and implications for practice 2

Revisions to the Guideline 3

Preamble 4

Living Guideline process 4

Autistic preferences around terminology 5

Māori perspectives 6

Tiriti o Waitangi/Treaty of Waitangi 7

Target audience 7

Part 1: Introduction 8

1.1 Background 8

Concepts of sex and gender 8

Sex/gender differences in the prevalence of autism 9

Sex/gender differences in different domains of autistic characteristics 10

Age of diagnosis 11

Sex/gender differences in autistic masking 11

1.2 Diagnostic process in Aotearoa New Zealand 13

1.3 Sex/gender differences in assessment in the Guideline 13

1.4 Preliminary scoping of international literature 14

1.5 The current review’s objectives and aims 15

Review objectives 16

Review aims 16

Part 2: Umbrella review 17

2.1 Method 17

Identification of studies 17

Study selection 17

Population 20

Phenomena of Interest 20

Context 20

Study designs 20

Exclusions 21

Superseded evidence 21

New Zealand-based primary research 22

Critical appraisal of included studies 22

Synthesis of included studies 22

2.2 Body of evidence 22

Overview 22

Scope 26

Study quality 26

Search strategy 26

Narrative summary of included secondary studies 28

Aotearoa New Zealand research 34

2.3 Summary and Discussion 35

Sex/gender differences in autistic characteristics 36

Sex/gender differences in age of autism diagnosis 38

Sex/gender differences in masking autistic characteristics 38

Aotearoa New Zealand research 39

Limitations of the umbrella review 40

Limitations of the evidence base 41

Future research 42

2.4 Conclusions 43

Overview 43

Key findings 43

Implications for practitioners 45

Part 3: Recommendation development 46

Decisions of the Living Guideline Group 46

Preamble 46

New Recommendations and Good Practice Points 47

Appendix 1: Methods 47

A1.1 Acknowledgements 47

Living Guideline Manager 47

Living Guideline Group (LGG) 47

Ex-officio LGG members 47

Other support 49

Funding 49

Declarations of interest 49

A1.2 Search strategy 49

Databases 49

Search terms 49

Grey literature 50

New Zealand-based qualitative research 50

A1.3 Study selection 50

Levels of evidence 50

Definition of systematic reviews 50

Study designs considered for New Zealand based research 50

A1.4 Data extraction 50

A1.5 Critical appraisal 50

A1.6 Preparing Recommendations 50

A1.7 Consultation 50

Appendix 2: Abbreviations and glossaries 49

A2.1 Abbreviations and acronyms 49

Miscellaneous Terms 49

Tests, scales and measures 49

Databases 50

A2.2 Glossary of terms 50

A2.3 Glossary of Te Reo Māori terms 54

A2.4 Pacific peoples terms 55

Appendix 3: Evidence Tables of included studies 54

References 70

List of Figures and Tables

[Figure 1](#fig1): Overall flowchart of articles screened 18

[Table 2.1](#Table2_1): Inclusion and exclusion criteria for selecting eligible studies 19

[Table 2.2](#Table2_2): Studies relating to sex/gender differences in characteristics of autism 23

[Table 2.3](#Table2_3): Studies relating to sex/gender differences in the age of autism diagnosis 24

[Table 2.4](#Table2_4): Studies relating to sex/gender differences in masking of autistic characteristics……………………….. 25

[Table 2.5](#Table2_5): Summary of sex/gender differences in presentation of autistic characteristics…………………………..29

[Table 2.6](#Table2_6): Summary of sex/gender differences in age of diagnosis …………………………..………………………………..33

[Table 2.7](#Table2_7): Summary of sex/gender differences in autistic masking …………………………..………………………………..33

[Table A1.1](#TableA1_1): Critical appraisal checklist for systematic reviews and research synthesis 53

[Table A1.2](#TableA1_2): Grades for Recommendations 54

[Table A3.1](#TableA3_1): Sex/gender differences in autistic characteristics 60

[Table A3.2](#TableA3_2): Sex/gender differences in age of autism diagnosis 66

[Table A3.3](#TableA3_3): Sex/gender differences in autistic masking 68

Haere i muri i te tuarā o Te Whāpuku

We can achieve success by following  
the lead of a person with great mana

This report is dedicated to **Amanda Bleckmann**, Deputy Chief Executive of Commissioning, Delivery and Design at Whaikaha – Ministry of Disabled People.

We are deeply grateful for her unwavering commitment and dedication to evidence-based practice which has shaped the development of the living guideline, ensuring it remains responsive to the latest research and the evolving needs of autistic individuals and their whānau.

Amanda’s leadership and commitment to enhancing the lives of autistic communities has been instrumental in driving this important mahi forward.

Arohanui

Executive Summary

This report supplements the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (‘the Guideline’) [1] by updating it in relation to sex/gender differences in the presentation of autism.

Scope

This umbrella review (“review of reviews”) considered research relating to sex/gender-based differences in autistic characteristics of children, adolescents and adults which are relevant to the recognition and diagnosis of autism.

In the current review, where it is unclear whether biological sex or gender is intended, the term ‘sex/gender’ is used to acknowledge this lack of clarity. The terms ‘male’ and ‘female’ are used to reflect the binary categories that are usually employed in study intake forms, and are acknowledged as similarly imprecise indicators of sex/gender.

Method

A ‘best evidence’ approach was employed to restrict eligible studies to peer reviewed systematic reviews and meta-analyses published since 2018.

A broad search strategy was undertaken of 15 bibliographic and guideline databases to identify peer reviewed studies published between January 1, 2018 and 18 October, 2023. In addition to citation searching of bibliographies, 1607 unique abstracts were considered.

The umbrella review included 10 systematic reviews [[16-25](#_ENREF_16)], five of which included meta-analyses. These were critically appraised for quality using a formal checklist.

No New Zealand-based systematic reviews were identified. However, to provide local cultural and service context, a search was undertaken for primary research conducted in Aotearoa New Zealand, published since 2004. Four research studies were included.

Umbrella review findings

Of the 10 included reviews, six considered sex/gender-based differences in the presentation of autistic characteristics, two investigated whether sex/gender impacted on timing of diagnosis, and two examined sex/gender differences in autistic masking of autistic characteristics.

Sex/gender differences varied dependent on whether there was accompanying intellectual disability, and how social communication and social interaction was framed and measured.

Female autistic individuals with an intellectual disability (ID) presented with slightly more difficulties in the broad social communication and social interaction domain (when assessed by diagnostic instruments) compared with autistic males with ID. For autistic people *without ID*, the data is more uncertain.

When assessed more narrowly (subtly, and using specific behavioural exemplars), autistic females presented with fewer difficulties in the specific ways their social communication and social interaction compared with autistic males.

There was no consistent evidence of sex/gender differences in ‘motor stereotypies’/repetitive body movements, or sensory patterns. However, differences emerged in sensory difficulties as a function of accompanying intellectual disability. In autistic people with ID, females had fewer sensory difficulties than males. By contrast, autistic males *without ID* presented with slightly fewer sensory difficulties than autistic females without ID.

There was no difference in Restrictive and Repetitive Behaviours and Interests (RRBI) for autistic people with ID. Autistic females without ID had slightly fewer RRBI than males *without ID*.

Females self-reported having more autistic characteristics than males in two studies, whereas sex/gender differences were not observed in two studies using clinician-rated diagnostic tools. Two systematic reviews reported uncertain evidence that female autistic people are diagnosed later than male.

Autistic masking involves the use of behaviours and strategies to adapt to, or cope within, a largely non-autistic social world. There is preliminary evidence that autistic females exhibit masking more than autistic males. However, results were mixed and limitations preclude firm conclusions at this time.

New Zealand-based research echoes concerns raised by international research.

Conclusions and implications for practice

* When considering the possibility of referral or diagnosis for autism, practitioners should be aware of the diversity of presentations of autism and consider the possibility of gender-based differences in autistic characteristics.
* In assessment for autism, individuals presenting characteristics should be compared with reference to those of non-autistic peers of the same gender and intellectual abilities.
* Masking of autistic characteristics can occur regardless of age or gender. Support goals should be consistent with creating an environment where autistic people can be safely and authentically autistic.
* When assessing characteristics for autism, clinicians and practitioners should be aware that diagnostic characteristics of autism may present differently to stereotypically male presentation, particularly for individuals who are (cisgender) female/girls/women, transgender, non-binary, and/or genderfluid.

Revisions to the Guideline

The evidence from the umbrella review, alongside consideration of relevant New Zealand research, informed the Living Guideline Group (LGG), an expert advisory panel, in developing the new or revised Recommendations and Good Practice Points presented below. These decisions and their rationale are presented in [Part 3](#Part3).

Summary Table: Revised and new Recommendation and Good Practice Points

|  |  |  |
| --- | --- | --- |
| Reference | New recommendation/GPP | Grade |
| Rec 1.2.14a | When considering referral or diagnosis for autism, practitioners should be aware of the diversity of presentations of autism and consider potential gender-based differences in autistic characteristics. | B |
| GPP 1.2.14b | When considering referral or diagnosis for autism, an individual’s presentation should be compared to those of non-autistic peers of the same gender and intellectual abilities.  In assessment, clinicians and practitioners should be aware that diagnostic characteristics of autism may present differently to stereotypically male presentation, particularly for individuals who are (cisgender) female/girls/women, transgender, non-binary, and/or genderfluid. | ✓ |
| Rec 1.2.14c | Masking of autistic characteristics can occur regardless of age or gender identity. Clinicians and practitioners should consider the possible presence of autistic masking. | A |
| GPP 1.2.14d | An autistic-friendly environment for assessment should be provided where the autistic person can be safely and authentically autistic. | ✓ |
| Rec 3.4.4a | Masking of autistic characteristics can occur regardless of age or gender identity. Educators and learning support practitioners should consider the possible presence of autistic masking. | A |
| GPP 3.4.4b | An autistic-friendly environment should be provided in classrooms and schools where the autistic learner can be safely and authentically autistic. | ✓ |
| Rec 5.2.9a | Masking of autistic characteristics can occur regardless of age or gender identity. | A |
| GPP 5.2.9b | An autistic-friendly environment should be provided in the community where autistic people can be safely and authentically autistic. | ✓ |

Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. Grade A indicates good evidence, B is fair evidence, C is international expert consensus, and I is insufficient, poor quality, or conflicting evidence. See [Table 1.2](#TableA1_2) in Appendix 1 for detail.

Preamble

Living Guideline process

The first edition of the New Zealand Autism Spectrum Disorder Guideline (as it was then called) was published in April 2008 [[26](#_ENREF_26)]. As part of their commitment to its implementation, New Zealand’s Ministry of Health and Ministry of Education agreed to establish a ‘Living Guideline process’ in 2009. This process aims to ensure that the Guideline is regularly updated and refined to reflect new research and changing user needs.

Every year, the Living Guideline process produces an update of the Guideline on a topic of high priority. These are published as Supplementary Papers, with fourteen completed to date [[2-15](#_ENREF_2)].

Revisions to Guideline Recommendations are undertaken by an advisory panel called the Living Guideline Group (LGG). The panel includes members with lived experience, clinicians, researchers, educationalists, and community service providers, as well as ex-officio representation by the funders: Whaikaha – Ministry of Disabled People and the Ministry of Education (the current membership is listed in [Appendix 1.1](#A1_1)). The Living Guideline process is directed by the Autism/Takiwātanga Guideline Manager (Marita Broadstock, INSiGHT Research) who also prepares the Supplementary Papers and revises the Guideline.

Each year, the Living Guideline Group are responsible for identifying and selecting a topic for update. A systematic literature review is then undertaken by the Autism/Takiwātanga Living Guideline Manager. A draft of the review (representing [Part 1](#Part1) and [Part 2](#Part2) of the Supplementary Paper) is considered by the LGG who assess the body of evidence with respect to its quality, quantity, consistency, applicability, and relevance. The LGG use this assessment as a basis for revising and developing new guideline Recommendations and Good Practice Points. These decisions are presented, accompanied by the LGG’s rationale and additional notes, in [Part 3](#Part3).

A second edition of the Guideline was published in 2016 [[27](#_ENREF_27)]. The current 3rd edition, now titled ‘Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau’ (henceforth, the Guideline), was published in 2022 [1]. New editions of the Guideline incorporate revised and new Recommendations from completed Supplementary Papers alongside other revisions.

The current Supplementary Paper should be read in the context of the Guideline and previous Supplementary Papers.

Full details of review methods including search strategies, appraisal of study quality and data extraction are presented in [Appendix 1](#App1).

[Appendix 2](#App2) presents relevant abbreviations, acronyms, and [glossaries](#Glossary).

[Appendix 3](#App3) presents evidence tables of appraised studies.

Autistic preferences around terminology

In this paper and in the Guideline, the terms ‘autistic person’ and ‘person on the autism spectrum’ are used to refer to someone understood to meet criteria for the diagnosis of Autism Spectrum Disorder. This reflects that increasingly people in the autistic community prefer to use identify-first language by referring to themselves as autistic rather than ‘having autism’. This recognises autism as a central part of one’s identity – of who one is, rather than as something separate to oneself, that can be put aside [[28](#_ENREF_28)].

Many autistic people are also uncomfortable with the acronym ASD. This is because the word ‘disorder’ conveys a sense of autism as a pathological impairment rather than a reflection of neurodiversity [[29](#_ENREF_29)]. Here, the acronym ASD is therefore only used when referring to a person’s clinical diagnosis or diagnostic tools or services.

The term ‘high functioning’ is sometimes used by researchers to define people with higher cognitive functioning either as established by intelligence tests (generally indicated by full-scale IQ scores of 70 or above), or through the diagnosis of ‘high-functioning autism’ or Asperger syndrome (under DSM-IV criteria) [[30](#_ENREF_30)]. In general, the terms ‘high functioning’ and ‘low functioning’ to describe groups of autistic people are considered unhelpful and divisive by many on the autism spectrum [31]. Some people may be described as having high and complex needs, and others as having lower or less obvious support needs.

The terms ‘problem behaviour’ and ‘challenging behaviour’ are avoided in the Guideline and its supplements. The use of ‘problem behaviour’ can be perceived as implying that the autistic individual is deliberately doing something wrong or ‘being naughty’ or ‘difficult’. However the behaviour is the problem, not the person, and the challenge lies in how to support them. The behaviour may be a concern to the autistic individual themselves (such as self-harm) or it may only be a concern to others who do not understand its purpose (e.g., shutdown from sensory overload). Addressing this concern therefore does not necessarily imply the need to eliminate or replace the behaviour. In specific situations, where possible, the ‘behaviour of concern’ should instead be described with respect to the autistic person’s experience (e.g., sensory overload, stimming, expression of distress).

Other problematic terms refer to autistic people who can reliably use speech to communicate as being ‘verbal’, and those who do not as being ‘non-verbal’. However, verbal language is not just speech and includes spoken and written words, signs or visual codes. To be more inclusive, alternative terms include ‘minimally speaking’ or having ‘complex communication needs (CCN)’. In the Guideline, people described as ‘having speech’ are those who can consistently rely on speech for functional communication. Note that non-verbal means something different when describing non-symbolic communication such as body language, facial expressions, tone of voice, and eye gaze to convey meaning.

It is understood that language preferences may continue to evolve. Fundamentally, autistic individuals have the right to self-refer and be referred to as they choose. It’s always best to ask a person what terms work for them, based on their own lived experiences and identity.

Examples of other language changes aimed at de-pathologising the condition include replacing the term ‘comorbidity’ with ‘co-occurring’; ‘normal’ with ‘non-autistic’; ‘symptoms’ with ‘characteristics’; and the terms ‘impairments’ and ‘deficits’ with ‘challenges’ and ‘difficulties’. Terms relating to ‘treatment’, and ‘management’ are generally avoided, especially where they are used in relation to the nature and expression of autism itself. Instead, they have been replaced by ‘supports’, and ‘approaches’.

The current review includes a discussion of autistic masking to describe any behaviour, strategy or process used to adapt to, or cope within, a largely non-autistic social world. Many other overlapping terms are used in the literature to describe this range of processes, including social camouflaging, passing as non-autistic (PAN), adaptive morphing, mimicry, imitation, compensation, accommodation, and assimilation. Whilst there is currently no consensus about what terms to use, some of these terms are considered inappropriate as they suggest autistic people are trying to make up for something lacking. The author was guided by autistic researcher Dr Ruth Monk in using ‘masking’ as a broad umbrella term in this Supplementary Paper. Ruth, who developed a language guide for researchers after wide consultation with fellow autistics in Aotearoa New Zealand [[32](#_ENREF_32)], advised that this term was currently the most widely used and acceptable in the autistic community. It should be noted that masking refers to autistic masking, as distinct from ethnic or gender masking used in other contexts. Within reference to appraised studies, the terms used by the authors are employed.

Māori perspectives

Takiwātanga is a Māori word for autism (it is also sometimes used to describe a person as autistic, as in “my daughter is takiwātanga”). This term was coined by Keri Opai after consultation with tāngata whaitakiwātanga (autistic people). It means ‘in my/their/his/her own time and space’ and, as Opai notes, it reflects “a positive, Māori worldview aspect of autism [[33](#_ENREF_33)].”

‘Tangata whaitakiwātanga’ refers to an autistic person

‘Tāngata whaitakiwātanga’ refers to autistic people

Māori cultural concepts and values not only determine how takiwātanga is perceived but also attitudes towards it and how autistic whānau should be supported. Sir Mason Durie (1984) [[34](#_ENREF_34)] provides a helpful framework to guide services and programmes for tāngata whaitakiwātanga and their whānau. Durie’s Whare Tapa Whā model lists four dimensions of wellbeing for Māori. These are: taha tinana (physical wellbeing); taha hinengaro (mental wellbeing); taha wairua (spiritual wellbeing) and taha whānau (family wellbeing). Consequently, in order to be culturally responsive, provisions for tāngata whaitakiwātanga need to incorporate these four dimensions.

A framework that complements Te Whare Tapa Whā is Ka Hikitia’s Outcome Framework[[1]](#footnote-1), Aotearoa New Zealand’s Māori Education Strategy. This is based on extensive consultation and is focused on achieving the following ‘excellent and equitable outcomes’ for Māori:

* Te Whānau: education provision responds to Māori within the context of their whānau
* Te Tangata: Māori are free from racism, discrimination and stigma
* Te Kanorautanga: Māori are diverse and need to be understood in the context of their diverse aspirations and lived experiences
* Te Tuakiritanga: Identity, language and culture matter for Māori
* Te Rangatiratanga: Māori exercise their authority and agency

Tiriti o Waitangi/Treaty of Waitangi

The Guideline and its Supplementary Papers acknowledge and uphold the principles of Te Tiriti o Waitangi/The Treaty of Waitangi. It considers the Treaty principles of partnership, participation and protection central to improving health and education outcomes for Māori.

Consistent with Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan [[35](#_ENREF_35)], the Guideline and this Supplementary Paper seek to advance practices and services for tāngata whaitakiwātangaMāori that uphold the significance of te reo Māori, te ao Māori (the Māori world), and ensure access to Māori approaches to practice.

This vision sees tāngata whaitakiwātangaMāori having leadership, choice and control over the supports which enable them to thrive, flourish and live the life they want.

Target audience

The systematic review presented in [Part 1](#Part1) and [Part 2](#Part2) aim primarily to provide an updated synthesis of research evidence on a specific topic for consideration by the Living Guideline Group. As such it is written in an academic style and is not intended for the general reader, though it will be of interest to researchers and those wishing to consider the original research in greater depth.

The Living Guideline Group’s decisions regarding the systematic review’s implications for revising and developing new Recommendations and Good Practice Points (which update the Guideline) are presented in [Part 3](#Part3). This section is intended for a broader audience, including tāngata whaitakiwātanga, their families/whānau, and the providers of professional clinical, education and support services for New Zealanders on the autism spectrum, as well as policy makers and funders.

Part 1: Introduction

1.1 Background

Concepts of sex and gender

Sex and gender are inter-related and overlapping concepts of (biological) sex and (sociocultural) gender.

As defined by the World Health Organisation (2010) cited by Libsack et al [[25](#_ENREF_25)], ‘gender’ is a socially defined construct used to describe behavioural attributes which varies across cultures and time. Similarly, Stats NZ describe gender as referring to an individual’s social and personal identity and/or gender expression [[36](#_ENREF_36)]. This may be described as (cisgender) male/man, (cisgender) female/woman, transgender woman, transgender man, non-binary, genderfluid and/or another gender identity (e.g., agender, bigender, and more)[[2]](#footnote-2).

By contrast, ‘sex’ is based on a person's sex characteristics, including their chromosomes, hormones, and reproductive organs [[36](#_ENREF_36)], and is typically assigned as observed and recorded in infancy. A person’s sex can change over time, for example a person assigned female at birth (AFAB) may later change their biological sex characteristics through taking hormone replacement therapy, or having surgery. This is particularly significant in autism research because of accumulating evidence suggesting higher prevalence of gender dysphoria/incongruence, transgender, non-binary, and/or genderfluid identities represented in the Autistic community compared with the general population [[37-39](#_ENREF_37)]. In Aotearoa New Zealand, a comprehensive national survey into the health and wellbeing of trans and non-binary people found that 22% of participants described themselves as neurodivergent [[40](#_ENREF_40)].

There is significant variability in reporting of participant characteristics in autism research [[20](#_ENREF_20), [22](#_ENREF_22), [25](#_ENREF_25)]. Researchers rarely differentiate between biological sex and gender, often using the terms interchangeably. This problem extends to health research where measurement of gender identity typically lacks best practice two-step methods in assessing both sex assigned at birth and current gender identity [[41](#_ENREF_41)].

In the current review, where it is unclear whether biological sex or gender is intended, the term ‘sex/gender’ is used to acknowledge this lack of clarity.

Use of the terms ‘male’ and ‘female’ reflect the binary categories that are usually employed in study intake forms. For the majority of participants, particularly in studies of young children, male and female are cisgender categories reflecting sex assigned at birth. However it is acknowledged that these are imprecise indicators of sex/gender that are filtered through researchers', parents’, or participants' interpretation of what is being asked. And so, male and female may variously refer to biological sex, sex assigned at birth, sex of rearing, and/or gender identity, and may change over time.

See the [limitations section](#LimEvBase) for further discussion.

Sex/gender differences in the prevalence of autism

No national population-based prevalence study of autism has been conducted in Aotearoa New Zealand. However several studies conducted using different ascertainment methods and cohorts [[42-44](#_ENREF_42)] reveal an approximate 4:1 male to female gender ratio in autism prevalence. This is consistent with international data (median estimate = 4.2), although the range of ratios in prevalence estimates across countries is very wide (0.8–6.1) [[45](#_ENREF_45)].

Notably, earlier studies observed that whilst females are less frequently diagnosed as autistic, they may also more likely to be ‘severely’ affected [[46](#_ENREF_46)] (that is, having higher and more complex support needs), on average. As recently systematically reviewed by Zeidan et al (2022) [[45](#_ENREF_45)], autistic females are more likely than autistic males to exhibit more ‘severe’ autistic characteristics, with a higher proportion of autistic females having an accompanying intellectual disability than males. Specifically, the male to female ratio is higher (10:1) in individuals with higher IQs, and lower (2:1) in individuals with co-occurring intellectual disability (ID) [[47](#_ENREF_47)].

To explain this significant variation, some theories have suggested biological (male) sex as an aetiological factor (given that sex commonly correlates to gender). Such models presume ‘male’ to mean ‘cisgender male’ and ignore transgender men. The problematic [[48](#_ENREF_48)] ‘extreme male brain’ theory [[49](#_ENREF_49)] suggests autistic individuals process the world through a ‘male’ lens and take an interest in stereotypically male topics, whilst having trouble with tasks that females are supposedly better at, such as grasping social cues. An alternative theory for the gender disparity is the ‘female protective effect.’ This suggests that females require a greater genetic/environmental ‘load’ than males to be affected [[50](#_ENREF_50), [51](#_ENREF_51)]. It has also been theorised that females with a higher IQ have better adaptation and compensation abilities than their male peers which prevent autistic characteristics reaching a diagnostic threshold [[52](#_ENREF_52)].

Note that consistent with the strengths-based kaupapa of the Autism Guideline, caution should be taken in discussing theories relating to causation. This discussion can be used to frame autism as a condition to be avoided or cured. These models will not be explored in any depth as they are not considered relevant to improving the lives of autistic people.

Complicating inference about sex as a biological factor is accumulating evidence that females have historically been under-diagnosed in the community across the lifespan [[53](#_ENREF_53)]. There has been increasing research interest in the contribution of ascertainment biases rooted in sociocultural and gendered contexts [[54-56](#_ENREF_54)]. Such biases may contribute to the wide variation of male-to-female ratios exhibited in prevalence statistics.

A meta-analysis by Loomes et al [[56](#_ENREF_56)] compared active case-finding methods (i.e., where a population is screened to identify possibly autistic children who then receive professional diagnostic assessment) with passive case-finding methods (i.e., where databases are reviewed or parents contacted to identify whether children have received an autism diagnosis). The researchers found that the male-to-female ratio was significantly smaller in active case-finding studies than passive case-finding studies (3.25 vs. 4.56). This difference suggests a diagnostic gender bias such that there are females in the general population who fulfil criteria for ASD but have not received an autism diagnosis.

As reviewed by Zeiden et al (2020) [[45](#_ENREF_45)], some researchers have argued that current assessment practices for autism are not optimised for females. These concerns are shared by diagnosing clinicians [[57](#_ENREF_57)]. As diagnostic criteria are based predominantly on behavioural descriptors, they may be biased towards a male manifestation of the condition, particularly as they have been developed and validated using samples which are dominated by males [[58-60](#_ENREF_58)]. There has been a growing awareness of gender biases in assessment. In recent years there has been a proportionate increase in diagnosis of adult females (from data in Australia and the UK) which may reflect changing recognition and assessment patterns [[61](#_ENREF_61), [62](#_ENREF_62)].

Sex/gender differences in different domains of autistic characteristics

Research suggests that autism may manifest differently in males and females with some autistic characteristics being more likely to be recognised in some genders than others, which may be a reflection of differing interests. For example, research suggests autistic males are more likely to play video games, whereas autistic females are more likely to talk with their friends [[63](#_ENREF_63)]. As reviewed in the Scottish autism Guideline [[53](#_ENREF_53)], while autistic males and females experience pervasive difficulties in developing and maintaining friendships, females appear to be more motivated to have friends and fit in with their peers than males [[64](#_ENREF_64), [65](#_ENREF_65)]. Descriptive research also suggests that young females may have more socially appropriate restricted interests (for example; horses, dolls, or pop stars) than those of young males, which are less likely to be considered unusual or indicative of autism [[64](#_ENREF_64), [65](#_ENREF_65)].

It has been suggested that gender differences in diagnosis may reflect interpretation biases due to differing gender-based norms. For example, clinicians/practitioners may hold inaccurate and sexist stereotypes, such as autism being a male-condition. This theory has been criticised as exacerbating the barriers autistic female individuals face when seeking a diagnosis, and contributing to their under-diagnosis [[52](#_ENREF_52), [66](#_ENREF_66), [67](#_ENREF_67)]. Gendered misconceptions and male-dominated stereotypes of autism were identified as barriers contributing to delayed diagnosis in a small study of New Zealand women [[68](#_ENREF_68)].

As discussed by Mahendiran et al (2019), there may also be an “interpreting bias” [[69](#_ENREF_69)] such that – despite comparable levels of autistic characteristics – parents may differentially interpret behaviour based on gender. For example, social withdrawal in females may be perceived as shyness, but an indicator of autism in males [[22](#_ENREF_22)]. A study by Hiller et al. (2016) [[70](#_ENREF_70)] illustrated how expectations impact caregivers' expectations of typical behaviour. Caregivers reported more concern for female children who display externalizing behaviours compared to males, whereas internalizing behaviours caused more concern for caregivers of male children compared to females.

These potential biases may contribute to autism being under-recognised in females compared with males. However to date, their contribution is difficult to quantify. Zeiden et al (2022) conclude that “while male sex can reasonably be used as a biological indicator, the impact of ascertainment issues on prevalence estimates is unknown” (p. 44) [[45](#_ENREF_45)].

Age of diagnosis

Characteristics of autism can often be seen before 12 months of age, with a stable clinical diagnosis possible for many children by 24 months, when the signs of atypical development are clear [[71](#_ENREF_71)]. An earlier diagnosis is important as it permits increased understanding of the child’s needs as well as the earlier introduction of supportive approaches and accommodations aimed to improve outcomes and quality of life. Regrettably, delays in diagnosis are common, and there is considerable variation in the age of diagnosis internationally, ranging from between two and ten years across studies, and averaging around 5 years [[17](#_ENREF_17), [21](#_ENREF_21)]. New Zealand survey data suggest an average age of diagnosis of 6.6 years [[72](#_ENREF_72)].

Factors that affect likelihood of diagnosis may also lead to delayed diagnosis. Delays in parents raising concerns about female children has been identified as a barrier to diagnosis and possible delayed diagnosis [[73](#_ENREF_73)]. The potential impact of gender on age of diagnosis is of interest in the current review.

Sex/gender differences in autistic masking

A rapidly growing area of research investigates the phenomenon of autistic masking/social camouflaging, terms broadly used in the literature to describe any process which aims to minimize, alter, or otherwise change the outward appearance of being autistic. Autistic masking/camouflaging has been more precisely defined as the conscious or unconscious employment of specific behavioural and cognitive strategies by autistic people to adapt to, or cope within, the predominately non-autistic social world [[74-77](#_ENREF_74)]. Examples of masking include making eye contact even if it makes you feel uncomfortable, or not talking about your interests too much for fear of being labelled ‘weird’ [[78](#_ENREF_78)].

Additional similar and overlapping terms have also been used, including ‘passing as non-autistic’ (PAN), adaptive morphing, mimicry, imitation, compensation, and accommodation. It is unclear whether the terms are being used consistently or whether there is a consensus in their meaning [[25](#_ENREF_25)]. As discussed in the Preamble (*see* [Autistic preferences around terminology](#Preamble_AutisticPreferences)), autistic researcher Dr Ruth Monk recommended ‘masking’ be used as an acceptable umbrella term which is widely used in the autistic community in Aotearoa New Zealand (*personal communication*, 23 November 2023).

Auto-biographical and qualitative accounts reveal that autistic people of all genders use a diverse range of masking behaviours and strategies. Examples include suppressing repetitive self-stimulating hand movements, using conversational scripts, forcing eye contact, and applying rules to respond to non-verbal cues in others [[23](#_ENREF_23)]. Such masking may enable autistic people to present a non-autistic social style, hide their autistic characteristics, and/or minimise recognition of social difficulties [[23](#_ENREF_23), [76](#_ENREF_76), [77](#_ENREF_77), [79](#_ENREF_79)], regardless of how convincing such attempts may be [[25](#_ENREF_25)].

Whilst non-autistic people can modify their social behaviour to present themselves more positively, autistic masking stems from a mismatch between their natural way of being and the demands of their environment. Masking therefore occurs in an environment where there is discrimination and can be considered a natural response to the ‘deficit narrative and accompanying stigma’ that has developed around autism [[78](#_ENREF_78)]. Whether masking is accompanied by positive or negative mental health outcomes is under investigation [[23](#_ENREF_23), [80](#_ENREF_80)]. Findings suggest higher self-reported camouflaging is associated with increased mental health difficulties [[23](#_ENREF_23)].

It should be remembered that not all autistic people are able to mask, and perspectives on advantages or disadvantages of masking can make some autistic people feel excluded. New Zealand autistic researcher Dr Ruth Monk comments on the complexities of these discussions (*personal communication,* 24 November 2023):

"The ability to "pass" as non-autistic (e.g., through masking), while obviously being something that takes a toll on us and is not something anyone should "have to do" for survival, can be seen as a privilege. Particularly for those who are unable to mask. It can cause a lot of frustration for people with higher support needs to hear only about how detrimental masking is without a recognition of the consequences of not masking.

I think we (Autistics) all ultimately agree that no one should have to mask. The reasons Autistic people who cannot mask wish they can are for personal safety, reduced prejudice, and reduced discrimination. All of which are a reflection of a problem with society, not a "divide" in our community."

Though the role of sex/gender in masking is keenly debated [[74](#_ENREF_74), [81](#_ENREF_81)], it has been suggested that sex-based differences in neurobiological, developmental, and cognitive factors, as well as gendered social expectations, may lead females to be more able and more likely to engage in masking than males [[25](#_ENREF_25)]. This is reflected in a small sample of autistic New Zealand women. Masking activities were described as coping strategies to comply with social and gendered expectations with the aim of mitigating experiences of difference and exclusion [[68](#_ENREF_68)].

A higher preponderance of masking in females could contribute to their autism being under-recognised [[54](#_ENREF_54)]. Alternatively there may be no specific sex/gender based differences. This issue is one of the areas being considered in the current review.

1.2 Diagnostic process in Aotearoa New Zealand

A brief overview of the diagnostic process is provided to provide a service context to assessment. This identifies relevant practitioners and settings where gender differences in the presentation of autistic characteristics may be observed.

The Autism Guideline [1] recommends that where possible a diagnosis for Autism Spectrum Disorder is made by a multidisciplinary team of two or more professionals with expertise in autism and related conditions: a paediatrician, psychiatrist, psychologist, speech-language therapist and/or occupational therapist. The diagnosis for younger children is usually facilitated by paediatric or multidisciplinary child development teams, and for adolescents via specialist child and adolescent mental health services (CAMHS) [[82](#_ENREF_82)].

The assessment usually involves observation in the clinic as well as early childhood centre/school/home as required, questionnaires from the early childhood centre/school, a developmental interview, and formal assessments as required. Surveys of clinicians suggest relatively low regular use of standardised autism assessments such as the ADOS-2 (61%) and the ADI (17%). Rates of use appear higher in assessments of children (>70%) than for adolescents (63%) or adults (30%) [[83](#_ENREF_83)].

Referrals can come from a range of sources, including health and development assessment in early childhood (e.g., by Well Child Tamariki Ora nurses), in educational settings, and by healthcare providers, such as general practitioners, who are trained to opportunistically elicit concerns regarding development. Research suggests that the majority of autistic children (72%) receive a diagnosis through the public system in a process taking, on average, 10.9 months [[84](#_ENREF_84)]. To avoid waits of several months, some parents seek diagnosis privately, through a psychiatrist, psychologist or paediatrician. However some data suggests diagnostic processes may be less rigorous in this setting [[83](#_ENREF_83)].

Children do not need a diagnosis to receive needs-based academic support in schools [[42](#_ENREF_42)]. However, families of children with relatively low support needs may be deemed ineligible for the service, requiring inequitable access to early supportive approaches through private (user-pay) services [[83](#_ENREF_83)].

Surveys of caregivers of autistic children in Aotearoa New Zealand indicate delays of up to three years between the time families first raise concerns in a professional consultation to formal autism diagnosis, with the mean age of diagnosis being 6.6 years [[72](#_ENREF_72)].

The pathway for adult autism assessments in Aotearoa New Zealand is less clear. Currently, formal diagnosis in the public system is only available to individuals who present to services with co-occurring significant mental health conditions. Survey data suggests that most adults are diagnosed in private settings by solo practitioners rather than within multi-disciplinary teams [[83](#_ENREF_83), [85](#_ENREF_85)].

1.3 Sex/gender differences in assessment in the Guideline

In the Aotearoa New Zealand’s Autism Guideline’s 3rd edition [1], there are no Recommendations relating to consideration of gender in the recognition, assessment or diagnosis of autism, however there is one relevant Good Practice Point 1.2.14 (see below). This was developed after the Living Guideline update on the implications of DSM-5 [[86](#_ENREF_86)] for the Guideline [[6](#_ENREF_6)]. There are no details provided on how gender may influence autism assessment. The current update is expected to provide evidence that will guide the development of recommendations and GPPs in this area.

|  |  |
| --- | --- |
| 1.2.14 *Assessment should consider the influence of diversity such as sense of self, ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographic factors* | **√** |

Consideration of gender, sexual development and sexuality were considered in the Living Guideline update on sexuality education for young people on the autism spectrum [[10](#_ENREF_10)]. One of the Good Practice Points (3.2.2.7a, also 6.24b) developed by the LGG from this update was that, “all those who support young people and adults on the autism spectrum should be sensitive to gender and sexual diversity”. Whilst that GPP was prepared within the context of sexuality education (which is out of scope for the current review), it remains applicable to services including within the context of recognition, assessment and diagnostic practices.

This GPP was also referred to in Part 4 of the Guideline on ‘Supportive approaches for mental health and wellbeing’ (p. 163) [1]. It occurs in the context of a discussion of proactive measures to ensure supports are accessible and appropriate to people from ethnic minority communities where it is noted that, “gender and sexual diversity may also be representative of a minority community”.

1.4 Preliminary scoping of international literature

A preliminary literature search was undertaken to inform the Living Guideline Group’s selection of areas of the Guideline [1] that were a priority to update. This topic was also prominent among research priorities of autistic adults, autistic youth, educators, practitioners and researchers identified in recent research conducted in Aotearoa New Zealand [[87](#_ENREF_87)]. As the role of gender in assessment was proposed as a potential topic of interest, a scoping search of the Cochrane Database and PubMed from 2013 was undertaken using the terms autism, systematic review, and (various terms for) gender combined in the ‘title’ field. Autism Guidelines from the UK [[88](#_ENREF_88)], Scotland [[53](#_ENREF_53)], and Australia [[89](#_ENREF_89)] were also searched. This scoping suggested that this was an active area of research, particularly since 2018 when research interest increased dramatically.

Some recent national Guidelines from other countries included recommendations relevant to sex/gender differences in autistic characteristics.

In 2016, Scotland’s SIGN Guideline included the following recommendation: “Healthcare professionals should consider that females with ASD may present with a different symptom profile and level of impairment than males with ASD” [[53](#_ENREF_53)].

The UK’s NICE guideline [[88](#_ENREF_88)] on the recognition, referral and diagnosis of children and young people on the autism spectrum included a recommendation that when considering the possibility of autism, one should be aware that “autism may be under-diagnosed in girls” (Section 1.2.5, p. 8).

Gender was also considered in the Australian Diagnostic Guideline (2018) [[90](#_ENREF_90)][[3]](#footnote-3). The reviewers concluded that behaviours that characterise autism may differ between genders, and that autistic females may be more likely to use compensatory strategies to ‘camouflage’ their autistic features. The following recommendation was developed, “It is recommended that all members of the Assessment Team consider the individual’s behavioural presentation and needs in comparison to other individuals of the same gender, and be aware of how ASD may manifest differently in males and females.”

1.5 The current review’s objectives and aims

Since 2018, there has been a rapid growth in research examining the variation in autistic characteristics as a function of sex/gender. Scoping of the literature identified several good quality systematic reviews and meta-analyses published over this time which led to the Living Guideline Group prioritising this topic for update.

The current Supplementary Paper presents an ‘umbrella review’ undertaken of peer reviewed secondary research studies (systematic reviews and meta analyses) where they investigated the consideration of sex/gender in the assessment of autism.

Umbrella reviews aim to provide a summary of existing research syntheses relating to a topic, rather than a re-synthesis of primary studies. This approach allows assessment of whether review teams addressing similar questions independently observe similar results and arrive at similar conclusions [[91](#_ENREF_91)]. Umbrella reviews also allow broadly scoped topics to be considered, comparing and contrasting the findings from a range of reviews with varying selection criteria. This permits consideration of the impact of different features of the research question, populations and outcomes of interest, and to determine areas of consistency and discrepancy.

In addition to the umbrella review, a review was undertaken to identify primary research undertaken in Aotearoa New Zealand relevant to sex/gender differences in autistic characteristics (see [Appendices A1.2](#A1_2) and [A1.3](#A1_3) for the methodology). Such work was considered to support interpreting the applicability and generalisability of the international evidence to New Zealand’s geographic, cultural, ethnic, and service context.

Review objectives

The current review update explores how an autistic person’s sex/gender may affect their assessment for a diagnosis of autism. As an umbrella review, the objective was to identify and summarise the latest secondary research findings which describe how autistic people may have different characteristics to their autistic peers based on their sex/gender. In addition, a person’s sex/gender or gender identity may influence the recognition of these characteristics, and the extent to which these characteristics may be masked.

This evidence was supplemented by a review of research from New Zealand of broader study designs published since 2004 to provide local ethnic, cultural, and service contexts.

This work was considered by the Living Guideline Group (LGG) (a multi-disciplinary advisory group) in developing Recommendations and Good Practice Points to improve the recognition, assessment and diagnosis of autism.

This work is expected to assist autistic individuals, families/whānau and other support providers and practitioners to consider the potential impact of sex/gender on an individual’s presentation of autism. Understanding how autism may manifest differently in males and females may improve recognition and referral of an autistic individual for diagnostic assessment and provision of support.

Review aims

The specific aims of this Supplementary Paper were:

* summarise systematic reviews and meta analyses relevant to whether there are sex/gender-based differences in the presentation of (core) characteristics of autism relevant to its diagnosis
* consider this evidence as it supplements the Guideline [1] in order to inform the LGG’s revision of any existing relevant Recommendations/Good Practice Points and the development of new ones.

Part 2: Umbrella review

This chapter describes the findings of an umbrella systematic review (a review of systematic reviews) relating to sex/gender-based differences in the presentation of the characteristics of autism relevant to its diagnosis.

2.1 Method

Identification of studies

A broad and inclusive systematic search was undertaken on 9–13 July 2023 and updated on 18 October 2023 using a combination of terms for autism, gender, and methodology (see [Appendix 1.2](#A1_2) for the full search strategy). Titles, abstracts and subject fields of four bibliographic databases and 11 health technology assessment and/or guideline databases were searched. Results were initially limited to those published in the English language; however, the search strategy was run again for non-English publications and identified no reports which met selection criteria for the current review.

Where database limits permitted, publications were restricted to those involving human participants and peer reviewed journals. Hand searching of journals and contacting of authors for unpublished research were not undertaken. To identify additional eligible studies, bibliographies of retrieved publications and recent narrative reviews were also examined. This led to 1160 unique abstracts being identified, after removal of duplicates.

Guidelines from the Preferred Reporting Items for Systematic Review and Meta-Analyses statement (PRISMA) [[92](#_ENREF_92)] were employed for the screening and selection process. The PRISMA flowchart is presented in [Figure 1](#fig1).

Study selection

Studies were selected if they met predefined inclusion criteria which were structured around parameters of the PICo approach: *Population*, phenomena of *Interest*, and *Context* (see [Table 2.1](#Table2_1)). This framework is suggested for research questions where the phenomena of interest (presentation of autism as a function of sex/gender) represents the outcome and is suited to syntheses of qualitative phenomena including lived experience [[93](#_ENREF_93)].

Papers were initially screened based on their title and abstract, and then potentially eligible papers were retrieved as full text and assessed for eligibility. As a paper may be excluded for multiple reasons, reasons for exclusion were identified sequentially from a list ordered as follows: wrong study design, wrong population, wrong comparator, wrong scope/intervention, and wrong outcomes. For each excluded paper, the first criteria that applied was recorded as the reason for exclusion, with results presented in [Figure 1](#fig1).

Figure 1: Overall flowchart of articles screened

**Identification of studies via databases and other sources**

Records identified from:

Databases (n = 1214):

Medline (n = 390)

CINAHL\* (n = 169)

PsycINFO (n = 175)

Embase (n = 461)s

Cochrane Library (n = 19)

Duplicate records removed *before screening*:

(n = 57)

**Identification**

Records identified from:

Citation searching (n=3)

Records excluded

(n = 1085)

Records screened

(n = 1160)

Reports excluded

Wrong Study Design (n = 12)

Wrong Population (n = 10)

Wrong Phenomena of interest (n = 34)

Wrong Context (n = 6)

Retrieved reports

(n = 75)

**Screening**

First set of studies meeting initial selection criteria

(n = 13)

Reports excluded after appraisal

No unique primary studies (n = 1)

Low review quality (n = 2)

**Included**

Final set of studies included in umbrella review

(n = 10)

\* searches excluded Medline records

Table 2.1: Inclusion and exclusion criteria for selecting eligible studies

|  |  |
| --- | --- |
| **Characteristic** | **Inclusion criteria** |
| Study Design | Systematic reviews (presented as a meta-analysis or a narrative synthesis) of relevant scope |
| Population | Autistic people of any age including comparisons of males and females (including transgender, nonbinary, and/or genderfluid identities, where reported). |
| Phenomena of Interest | Gender differences in the presentation of autistic characteristics relevant to diagnosis |
| Context | Presentation of individual characteristics relevant to a diagnosis of autism, including differences in how characteristics are manifested, the impact on referral for assessment and possible delayed diagnosis, and whether characteristics may be masked/camouflaged differently as a function of sex/gender. |
| Publication date | Peer reviewed articles published in English between 1 January 2018 and 18 October 2023 |
| **Characteristic** | **Exclusion criteria** |
| Excluded publication type | The following publications were excluded: dissertations, book chapters, conference proceedings, poster presentations, abstract-only reports, unpublished data, narrative reviews, editorials, correspondence, commentaries, book reviews, news reports, trade magazine articles, and blogs |
| Excluded scope | Studies which were not deemed relevant to the research question or nature of the review were excluded, including if:   * they concerned the development/evaluation of an intervention, screening/diagnostic/assessment tool, or outcome measure * their focus of study was inappropriate (e.g., aetiology, neuroimaging techniques, prevalence, co-occuring conditions, developmental trajectories, factors impacting likelihood of autism including biomarkers, accuracy of screening tools and universal screening programmes) * they were case studies, animal studies, prenatal studies, genetic studies, brain studies, biomarker studies, pharmacological studies * they did not disaggregate data by sex/gender |
| Superseded evidence | Limited to ‘best evidence’, excluded secondary reviews which included no unique primary studies (i.e., studies not included in other eligible reviews) |

Population

The study population were autistic people of any age and included comparisons of males and females (understanding that these terms may be imprecise with respect to reflecting biological sex and gender). Transgender, non-binary, and/or genderfluid identities were also included, where reported.

Sex/gender comparisons between autistic and non-autistic people were also of interest and were reported when included as additional comparisons.

Phenomena of Interest

Phenomena of interest included variations in autistic characteristics as a function of sex/gender (including males/boys/men, females/girls/women, transgender, nonbinary, and/or genderfluid identities , where reported). Autistic characteristics were those relevant to diagnostic criteria for ASD according to DSM-5. These relate to two main (‘core’) areas:

1. social communication and social interaction, such as:

* social-emotional reciprocity
* nonverbal communicative behaviours used for social interaction
* developing, maintaining, and understanding relationships

1. types of restricted, repetitive patterns of behaviour, interests, or activities, such as:

* stereotyped or repetitive motor movements, use of objects, or speech
* Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour
* highly restricted, fixated interests that are abnormal in intensity or focus
* hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.

Context

The context included the presentation of individual characteristics relevant to a diagnosis of autism, including differences in how characteristics are manifested, the impact on referral for assessment and possible delayed diagnosis, and whether characteristics may be masked/camouflaged differently as a function of sex/gender.

Study designs

The NHMRC evidence hierarchy [[94](#_ENREF_94)] ranks studies in terms of quality based on their study design (see [Table A1.1](#TableA1_1) in Appendix 1). The most robust level of evidence is Level I which consists of systematic reviews (which may include a meta-analysis) [[95](#_ENREF_95)]. Further details are presented in [Appendix 1.3.](#A1_3)

Guided by this hierarchy and the principal of ‘best evidence’, an umbrella review was undertaken of peer reviewed secondary research studies (systematic reviews and meta analyses) published in or later than 2018. Searching of research syntheses within the last five years yields primary research conducted in previous decades included in the identified systematic reviews.

Eligible systematic reviews (presented as a meta-analysis or a narrative synthesis) needed to meet the following criteria: (1) included a clear statement of the purpose of the review; (2) described the search strategy (including key search terms, multiple relevant databases, specification of search dates); (3) indicated the criteria used to select studies for inclusion; (4) and presented findings relevant to the scope of the current systematic review.

Exclusions

Publications were excluded if they were:

* Dissertations, book chapters, conference proceedings
* Poster presentations, abstract only reports, unpublished data
* Narrative reviews, editorials, commentaries, correspondence
* Book reviews, news reports, trade magazine articles, blogs
* Not deemed relevant to the research question or nature of the review, including studies that:
  + concerned the development/evaluation of an intervention, screening/diagnostic/assessment tool, or outcome measure
  + focused exclusively on research related to understanding aspects of autism outside of the assessment and diagnostic process (e.g., aetiology, neuroimaging techniques, prevalence, developmental trajectories, factors impacting likelihood of autism including biomarkers, accuracy of screening tools and universal screening programs)
  + reported on studies comparing autistic people with non-autistic people
  + compared autistic people with non-autistic people only (however reported where investigated in addition to eligible comparisons between autistic people)
  + did not include a mixed male/female population
  + were case studies, animal studies, prenatal studies, genetic studies, brain studies, biomarker studies, pharmacological studies
  + did not carry out comparisons on relevant outcomes according to sex/gender

Superseded evidence

Secondary reviews which included no original primary studies were also excluded. That is, reviews were excluded if they did not include at least one unique primary study meeting selection criteria for the current review not already included in a more recently published secondary review. This aimed to reduce redundancy of superseded material.

New Zealand-based primary research

To consider the applicability and generalisability of the evidence to Aotearoa, studies conducted in Aotearoa New Zealand were considered applying more inclusive selection criteria. Primary studies employing any design methodology (including qualitative research, with the exception of case studies) and published in peer reviewed Journals in or since 2004 were eligible for inclusion where they otherwise met selection criteria of the current umbrella review. This allowed consideration of research that reflects New Zealand’s unique geographic, cultural, ethnic, and service context.

Critical appraisal of included studies

An evidence table template was employed to record pre-defined information (see [Appendix 1.4](#A1_4)) to extract data from each included report ([Appendix 3](#App3)).

The quality of included systematic reviews was formally appraised using the Joanna Briggs Institute (JBI) quality checklist [[91](#_ENREF_91)] (see [Table A1.2](#TableA1_2), and [Appendix 1.5](#A1_5)). Scores categorised study quality as follows: low (score 0-5), medium (score 6-8), or high (score 9–11).

Synthesis of included studies

To identify any overlap of studies between included reviews, citations of their included studies were recorded in an excel table, with shared citations highlighted.

Results are presented narratively and in Tables. The secondary reviews are summarised with attention to strength and consistency of effects across similar studies, as well as differences, including comparing those of differing scope.

These findings represent the ‘body of evidence’ considered by the Living Guideline Group in developing Recommendations and Good Practice Points using a process described in [Appendix 1.6](#A1_6).

2.2 Body of evidence

Overview

After applying initial inclusion and exclusion criteria, 13 secondary studies published since 2018 were eligible for inclusion in the review and were critically appraised. After assessing these studies for study quality using the JBI checklist [[91](#_ENREF_91)], three were excluded. Two were excluded as being of low quality (scoring 3/11) [[96](#_ENREF_96), [97](#_ENREF_97)]. The Australian Guideline for the assessment and diagnosis of autism spectrum disorders in Australia [[89](#_ENREF_89)] was excluded as it included no unique primary studies in its evidence tables. Its findings are discussed in the Introduction as a relevant consensus practice guideline.

This left 10 studies included in the current umbrella review [[16-25](#_ENREF_16)]. Full extracted data are provided in the evidence tables (see [Appendix 3](#App3)). The studies relate to three distinct research areas and the summary characteristics are presented separately in [Table 2.2](#Table2_2), [Table 2.3](#Table2_3), and [Table2.4](#Table2_4), organised chronologically by year of publication (oldest first), and for publications in the same year, alphabetically (by first author).

Table 2.2: Studies relating to sex/gender differences in characteristics of autism

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Study | Design  Quality | Scope | Selection criteria | Studies identified |
| Ben-Sasson et al., (2019) [[16](#_ENREF_16)] | SR/MA  Medium quality (8/11) | Sex/gender differences in sensory responsivity (over and under) and sensation seeking | Published: June 2007 - June 2018  Population: Autistic people, of any age  Quantitative observational studies | k=55 studies  N=75,121 autistic people, M age =10.9 years; M=81% male |
| Mahendiran et al., (2019) [[18](#_ENREF_18)] | SR/MA  Medium quality (6/11) | Sex/gender differences in social interaction and communication | Published: < January 2020  Population: Autistic and non-autistic children/adolescents, 6 - 18 years  Quantitative observational studies | k=8 studies  N=576 autistic children/adolescents, M age range=8 - 13 years; M=69% male  N=538 non-autistic children/adolescents, M age range=8 -14 years; M=57% male |
| Huang et al., (2020) [[24](#_ENREF_24)] | SR  Medium quality (6/11) | Autism diagnosis in adulthood synthesised qualitative as themes, including gender | Published: 2008 - Nov 2018  Population: Autistics seeking diagnosis in adulthood English language  Quantitative, qualitative and mixed design observational studies | k=13 studies  N=17,994 autistic adults, age range 16 - 85 years; M=67% male |
| Melo et al., (2020) [[19](#_ENREF_19)] | SR  High quality (9/11) | Sex/gender differences in ‘motor stereotypies’/repetitive body movements | Published: < July 2018  Population: Autistic people, of any age  Quantitative observational studies | k=7 studies  N=1285 autistic people, M age range=5 - 19 years; M=66% male |
| Wood-Downie et al., (2021) [[22](#_ENREF_22)] | SR/MA  High quality (11/11) | Sex/gender differences in narrow construct subdomains for social interaction and communication | Published: < January 2020  Population: Autistic people, and nonautistic people, of any age  Quantitative observational studies | k=18 studies  N=1,431 autistic people, M age range=9 months - 36 years; M=53% male  N=1,311 non-autistic people, M age range=9 months - 40 years; M=42% male |

Table 2.2: Studies relating to sex/gender differences in characteristics of autism *(continued)*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Saure et al., (2023) [[20](#_ENREF_20)] | SR/MA  High quality (9/11) | Area of interest: Sex/gender differences in domains of social communication and social interaction; restrictive and repetitive behaviour and interests; sensory ‘problems’ | Published: < May 2022  Population: Autistic people without ID, and with ID, of any age  English language  Quantitative, qualitative and mixed design observational studies | k=79 studies  N=14,758 people  N=10,550 (72%) without ID; M age=15 years; M=70% male  N=4208 (28%) with ID; M age=9 years; M=70% male |

**Note:** Quality rating assigned using JBI checklist [[91](#_ENREF_91)] (see [**Appendix 1.5**](#A1_5))

**Key**: ADHD=Attention Deficit Hyperactivity Disorder; ID=intellectual disability; M=mean; MA=meta-analysis; SR=systematic review. See **Appendix 3,** [**Table A3.1,**](#TableA3_1) for Evidence Tables

Table 2.3: Studies relating to sex/gender differences in the age of autism diagnosis

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Study | Design  Quality | Scope | Selection criteria | Studies identified |
| Loubersac et al., (2021) [[17](#_ENREF_17)] | SR  Medium quality (8/11) | Area of interest: to identify average age at which ASD diagnosis is confirmed, and any associated factors including gender | Published: < Dec 2019  Population: Autistic children  English or French language  Quantitative observational studies | k=14 studies  N=75,121 autistic people, M age range 3 - 9 years; gender distribution not reported |
| Van ‘t Hof et al., (2021) [[21](#_ENREF_21)] | SR/MA  Medium quality (6/11) | Area of interest: to identify average age at which ASD diagnosis is confirmed, and any associated factors including gender | Published: 2012 - June 2019  Population: Autistic people of any age  English language  Quantitative observational studies | k=56 studies (20 analysing by gender)  N=120,540, age of diagnosis; M=31 - 574 months (2.5 - 47.8 years), gender=79% male sample, on average |

**Note:** Quality rating assigned using JBI checklist [[91](#_ENREF_91)] (see [**Appendix 1.5**](#A1_5))

**Key**: M=mean; MA=meta-analysis; SR=systematic review. See **Appendix 3,** [**Table A3.2**](#TableA3_2)**,** for Evidence Tables

Table 2.4: Studies relating to sex/gender differences in autistic masking

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Study | Design  Quality | Scope | Selection criteria | Studies identified |
| Cook et al., (2021) [[23](#_ENREF_23)] | SR  High quality (9/11) | Area of interest: autistic camouflaging (or masking or compensating) in children and adults with autism diagnoses or high levels of autistic characteristics | Published: Oct 2020 - May 2022 (updating an earlier review)  Population: Autistic of any age (diagnosed or with high levels of autistic characteristics)  English language  Quantitative and mixed design observational studies | k=29 studies (18 analysed by gender)  N=2254 adults, 29% male, 60% female\*, 8% other; 60% diagnosed in adulthood;  N=1077 children and adolescents, M age 11.9 years; 63% male, 37% female\*  \* Included those of female sex and those who identified as girls/women |
| Libsack et al., (2021) [[25](#_ENREF_25)] | SR  High quality (8/11) | Area of interest: passing as non-autistic (PAN) | Published: < May 2020  Population: Autistic people (diagnosed or self-identified) of any age  English language  Quantitative, qualitative and mixed design studies | k=46 studies (19 analysed by gender)  N=5980 people; M age=24 years; 49% females, 46% males, 3% neither (i.e., ‘non-binary’, ‘transgender’, ‘gender diverse’, ‘gender fluid’), 2% unreported |

**Note:** Quality rating assigned using JBI checklist [[91](#_ENREF_91)] (see [**Appendix 1.5**](#A1_5))

**Key**: M=mean; MA=meta-analysis; SR=systematic review. See **Appendix 3,** [**Table A3.3**](#TableA3_3)**,** for Evidence Tables

Scope

The 10 studies relate to three distinct research areas. Six [[16](#_ENREF_16), [18-20](#_ENREF_18), [22](#_ENREF_22), [24](#_ENREF_24)] considered sex/gender-based differences in characteristics of autism (see [Table 2.2](#Table2_2)). Four studies considered the expression of specific domains of autistic characteristics, including sensory issues [[16](#_ENREF_16)], social interaction and communication [[18](#_ENREF_18), [22](#_ENREF_22)], and ‘motor stereotypies’/repetitive body movements [[19](#_ENREF_19)]. A review of autism diagnosed in adulthood included comparisons of males and females with respect to either self-rated or clinician-rated autistic characteristics [[24](#_ENREF_24)]. The most broad-ranging review [[20](#_ENREF_20)] considered a range of core autistic characteristics including those relating to social communication and social interaction; restrictive and repetitive behaviour and interests; and sensory processing difficulties, more specifically.

Two studies [[17](#_ENREF_17), [21](#_ENREF_21)] considered whether the age that autism was diagnosed was moderated by sex/gender (see [Table 2.3](#Table2_3)).

Finally, two systematic reviews [[23](#_ENREF_23), [25](#_ENREF_25)] examined sex and gender-based differences in the masking of autistic characteristics (see [Table 2.3](#Table2_3)).

Of the 10 included systematic reviews, five included relevant meta analyses.

The 10 systematic reviews exhibited only small overlap between included primary studies. This was due to the varying selection criteria employed with respect to phenomena (autistic characteristic domains, time of diagnosis, autistic masking), populations (children or adults), and study designs (quantitative or qualitative) considered.

Study quality

Using the JBI checklist, review quality was rated as being of medium quality (scoring 6 – 8) in five studies, and of high quality in five studies (scoring 9 – 11). Studies considering autistic characteristics were evenly spread among these categories ([Table 2.2](#Table2_2)). Both of the reviews relating to age of diagnosis were rated as being of medium quality ([Table 2.3](#Table2_3)), and both the reviews investigating autistic masking were rated as of high quality ([Table 2.4](#Table2_4)). The selection criteria excluded studies graded as being of low quality (scoring 0 – 5).

As appropriate to the research questions, all reviews included quantitative comparative data drawn from observational studies including cross-sectional case series, longitudinal cohort studies, and secondary analyses of population-based cohort studies. Six included only quantitative studies [[16-19](#_ENREF_16), [21](#_ENREF_21), [22](#_ENREF_22)]. One review [[23](#_ENREF_23)] also included mixed design studies where a quantitative component was included. Three reviews included quantitative, qualitative and mixed design studies [[20](#_ENREF_20), [24](#_ENREF_24), [25](#_ENREF_25)].

Search strategy

With respect to literature searching employed, two reviews employed no language restriction to their search strategy [[19](#_ENREF_19), [22](#_ENREF_22)]. Seven reviews considered English language articles only [[16](#_ENREF_16), [18](#_ENREF_18), [20](#_ENREF_20), [21](#_ENREF_21), [23-25](#_ENREF_23)], and one included literature published in English or French [[17](#_ENREF_17)].

Study characteristics

Seven of the appraised reviews considered autistic people of any age [[16](#_ENREF_16), [19-21](#_ENREF_19), [23-25](#_ENREF_23)]. These included both studies investigating autistic masking, one of which also included people with high autistic characteristics [[23](#_ENREF_23)]. Two studies included studies of children and adolescents only [[17](#_ENREF_17), [18](#_ENREF_18)]. One review focused exclusively on autistic adults diagnosed in adulthood [[24](#_ENREF_24)].

Two of the appraised reviews also included non-autistic people [[18](#_ENREF_18), [22](#_ENREF_22)]. One review reported on autistic people with and without intellectual disability, separately [[20](#_ENREF_20)].

Synthesising study characteristics accurately across studies was limited by variable reporting approaches and some overlap in the populations of included studies (both within and across reviews). Findings should therefore be read as broadly indicative of the body of evidence, but slightly inflated.

Six studies exploring autistic characteristics reported on 174 studies where sex/gender differences were investigated, ranging from 7 to 79 studies ([Table 2.2](#Table2_2)). Summing across these studies, the studies report on 111,165 autistic people (range: 576 – 75,121), averaging 68% male (53% – 81%). Four studies included autistic people of any age [[16](#_ENREF_16), [19](#_ENREF_19), [20](#_ENREF_20), [22](#_ENREF_22)], one considered children and adolescents only [[18](#_ENREF_18)], and one adults only [[24](#_ENREF_24)]. Two studies also had control samples of non-autistic people [[18](#_ENREF_18), [22](#_ENREF_22)]. One included comparisons of 10,550 autistic people without an intellectual disability with 4,208 autistic individuals with an intellectual disability [[20](#_ENREF_20)].

Two studies investigating the age of diagnosis reported on 34 studies where sex/gender were compared, including 195,661 autistic people (see [Table 2.3](#Table2_3)). One considered young children aged 3 to 9 years [[17](#_ENREF_17)], whereas the other included people aged 2 to 48 years [[21](#_ENREF_21)]. The sex/gender ratio was only reported in one study [[21](#_ENREF_21)], and was found to be 4:1 male to female.

The two studies which considered autistic masking reported on 9,311 autistic people across 75 studies ([Table 2.4](#Table2_4)). One study [[23](#_ENREF_23)] considered adults (60% diagnosed in adulthood, 29% male, 60% female, 8% ‘other’) ) separately from children (mean age of 12 years; 63% male, 37% female, 0.3% ‘other’). ‘Other’ included transgender, non-binary, and/or genderfluid individuals. The other study [[25](#_ENREF_25)] considered people of any age averaging 24 years, 49% of whom were female, 46% male, 3% neither, and 2% unreported.

Readers are cautioned that the independent variable of sex/gender was reported inconsistently across studies. When considering reviews investigating the presentation of autism (Table 2.2), two studies reported on ‘gender’ [[16](#_ENREF_16), [24](#_ENREF_24)]; one on ‘sex’ [[18](#_ENREF_18)]; two referred to ‘gender’ and ‘sex’ interchangeably [[19](#_ENREF_19), [20](#_ENREF_20)]; and one reported on ‘sex/gender’ [[22](#_ENREF_22)]. The lack of consistency in reporting is compounded by many primary studies being unclear about whether they used sex or gender to define participants as female or male [[22](#_ENREF_22)].

Reviews of studies investigating the age of autism diagnosis referred to sex and gender interchangeably (Table 2.3). By contrast, rather than be restricted to binary categories for sex/gender, the two reviews considering masking (Table 2.4) reported on sex and gender separately and include a third option of ‘neither’ or ‘other’ (including specifically ‘non-binary’, ‘transgender’, ‘gender diverse’, ‘gender fluid’).

Narrative summary of included secondary studies

Studies are summarised individually below, and within each of the three research areas are presented in chronological order by date of publication, from oldest to most recent.

Studies investigating sex/gender differences in autistic characteristics

Six studies investigated sex/gender differences in autistic characteristics (see [Table 2.5](#Table2_5)).

Ben-Sasson et al., (2019) [[16](#_ENREF_16)]

An Israeli systematic review (assessed as being of medium quality) considered sensory patterns in autistic people compared with typically developing controls and those with other conditions. Studies including measures of sensory over-responsivity (SOR), sensory under-responsivity (SUR), and sensation seeking characteristics assessed across several sensory modalities including response to touch, sight, sound, taste, smell, and movement. Data from 55 studies and over 4,600 autistic people were included in meta-analyses.

Gender was found to have a non-significant moderating effect on sensory symptoms in the meta-analysis models undertaken. The authors argued that lack of an effect was due to the narrow range and variance of the male ratio leading to a skewed distribution among the compared studies. They suggested that more sensory data for autistic females is needed to investigate whether there are sex/gender differences in sensory patterns further.

Mahendiran et al., (2019) [[18](#_ENREF_18)]

In Canada, asystematic review with meta-analysis (of medium quality) was conducted exploring sex/gender differences in social-communication function in autistic children and adolescents (and people with ADHD) compared with typically developing individuals. Only data relevant to eight studies including over 500 autistic participants is reported here, all included social functioning outcomes and three also reporting on communication functioning.

In random effects model meta-analyses, no significant sex/gender differences were found within autistic group for social functioning, or for communication functioning, or for the typically developing group for either domain. There were also no sex/gender-based differences between the autism and typically developing groups. Significant heterogeneity was noted in all analyses. Measurement tool was a source of heterogeneity in the three studies investigating communication outcomes, acting as a significant moderator in the model. A sex/gender difference was observed for one outcome in one study.

The evidence base was limited by the small number of studies, small samples, and heterogeneity of measures/tools used (most were parent-reported). In particular, the low number of females in several studies may have led them to be underpowered to detect sex/gender differences. The reviewers suggest that larger longitudinal studies are required to address these and other methodological issues in order to have greater confidence in these findings.

Table 2.5: Summary of sex/gender differences in presentation of autistic characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Domain of interest | Study authors (year) | Population | Mean age (years) | Studies | Sex/gender differences | Fewer difficulties |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Autistic characteristics | | | | | | |
| Autistic characteristics *(self-rated)* | Huang et al (2020) [[24](#_ENREF_24)] | Autistic adults | 18-75 | K=2 | uncertain | Females |
| Autistic characteristics *(clinician-rated)* | Huang et al (2020) [[24](#_ENREF_24)] | Autistic adults | 18-75 | K=2 | No difference | NA |
| Social communication and social interaction | | | | | | |
| Social communication | Mahendiran et al., (2021) [[18](#_ENREF_18)] | Autistic | 8-13 | K=3 | No difference | NA |
| Social interaction | Mahendiran et al., (2021) [[18](#_ENREF_18)] | Autistic | 8-13 | K=8 | No difference | NA |
| Social communication/interaction | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic with ID | 9 | K=15 | SMD=0.20 (small) | Males |
| Social communication/interaction (narrow subdomain) | Wood-Downie et al., (2021) [[22](#_ENREF_22)] | Autistic | 0.8-36 | K=16 | SMD=0.39 (small to medium) | Females |
| Social communication/interaction | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic (no ID) | 15 | K=39 | SMD=-0.17 (uncertain) | Females |
| Restrictive and repetitive behaviours and interests (RRBI) | | | | | | |
| ‘Motor stereotypies’/repetitive body movements | Melo et al., (2020) [[19](#_ENREF_19)] | Autistic | 5-19 | K=7 | No difference | NA |
| RRBI | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic with ID | 9 | K=9 | SMD=-0.11 (no difference) | NA |
| RRBI | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic (no ID) | 15 | K=40 | SMD=-0.23 (small) | Females |
| Sensory processing | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic with ID | 9 | K=4 | SMD=-0.21 (small) | Females |
| Sensory processing | Saure et al., (2023) [[20](#_ENREF_20)] | Autistic (no ID) | 15 | K=18 | SMD=0.37 (small to medium) | Males |
| Sensory processing | Ben-Sasson et al., (2019) [[17](#_ENREF_17)] | Autistic | 11 | K=55 | No difference | NA |

**Key**: No colour (<0.15 = No difference), orange (0.15-0.20 = trend/uncertain effect), yellow (0.2<0.35 = small effect), green (0.35<0.5 = small to medium effect), NA=Not Applicable

Huang et al., (2020) [[24](#_ENREF_24)]

Australian researchers conducted a broad scoping review (medium quality) to summarise quantitative and qualitative research on autism diagnosis in adulthood, including studies of people who underwent or sought first-time diagnosis for ASD in adulthood, their carers, and practitioners who diagnose adults.

Findings were qualitatively synthesised into themes, one of which related to gender. Four studies reporting on sex/gender differences in autistic characteristics in over 1,600 autistic adults. Two studies reported that women tend to self-report more autistic characteristics then men [[98](#_ENREF_98), [99](#_ENREF_99)]. However two other studies found that women scored similar to men on clinician-rated diagnostic tools [[100](#_ENREF_100), [101](#_ENREF_101)]. The authors suggest that heightened social demands for women from increased involvement in social relationships may lead to increased awareness of their own difficulties [[99](#_ENREF_99)]. There is also the possibility that clinical measures are insufficiently sensitive to the presentation of autistic characteristics in women [[101](#_ENREF_101)].

These findings must be interpreted with caution given that the two studies reporting on autistic characteristics were small. Comparing rates of self-reported characteristics versus diagnostic scores is problematic given these studies are reporting on different populations.

Melo et al., (2020) [[19](#_ENREF_19)]

In Canada, systematic reviewers conducted an investigation (coded as being of high quality) of the prevalence of ‘motor stereotypies’/repetitive body movements in autistic people and considered whether gender may be associated (among other clinical and demographic factors). The authors acknowledged that the definition, classification and terminology used for motor stereotypies is highly variable and contentious. In their review, they defined motor stereotypies as repetitive body movements which were clearly differentiated and described separately from other repetitive behaviours. Meta-analyses investigating gender were not conducted due to insufficient data reporting on this variable.

A subset of seven studies analysed gender differences, reporting on nearly 1,300 autistic people. Only one study [[102](#_ENREF_102)] found a gender difference in the prevalence of motor stereotypies, and this was limited to autistic individuals who had low non-verbal IQ scores. In this group, females had significantly more stereotypies than males. This effect was not identified in the higher non-verbal IQ group.

The authors concluded that the data on the influence of gender on the prevalence of motor stereotypies was inconclusive. However, the review was limited by high heterogeneity, a low number of studies, use of convenience samples predominantly consisting of ‘high functioning’ (i.e., with less obvious autistic characteristics and average or above IQ) autistic people, and small samples that were underpowered to detect differences.

Wood-Downie et al., (2021) [[22](#_ENREF_22)]

Authors of a UK-based systematic review and meta-analysis (rated as being of high quality) reviewed research suggesting that current diagnostic/screening instruments may not capture gender differences and may have been biased by the small number of females included in their development and validation. In order to capture more subtle and specific sex/gender differences, the review focused exclusively on narrow construct/behavioural exemplars of social interaction and communication, based on fine-grained subdomains of the DSM5 diagnostic criteria, rather than abstract, broad construct measures typically reflected in ‘gold-standard’ instruments. Studies based on diagnostic/screening instrument scores at the broad construct level were excluded.

Studies compared within and between groups of autistic and non-autistic individuals. In random effects model meta-analyses, age group was also investigated as a moderating factor where heterogeneity was significant.

There were 16 relevant studies including over 1,400 autistic people. Studies considered a wide range of behavioural exemplars relating to peer relationships: (k=6 studies); play behaviours: (k=2); social attention: (k=3); and social reciprocity: (k=1). Outcomes were assessed through questionnaires, eye-tracking, observational measures, and behavioural tasks.

In analyses considering autistic people, there was a small to medium effect (SMD=0.39) such that autistic females expressed fewer social/communication difficulties than autistic males. This gender difference mirrored what was observed for non-autistic people (SMD=0.35).

As expected, both autistic females and males had significantly lower social interaction and communication skills than their nonautistic female and male counterparts, with medium to large effects. Age moderated some gender differences. The difference between nonautistic males and nonautistic females, and between autistic females and nonautistic females, became more evident with increased age. Whilst there was a trend that nonautistic males had fewer social/communication difficulties than autistic females, the difference was non-significant.

These findings suggest that autistic girls/women have better social and communication skills when assessed with measures focusing on narrow constructs that are quite different from those of diagnostic instruments. The authors argue that these narrow construct/behavioural exemplars may need to be reflected in the diagnostic process.

It was acknowledged that the findings are limited by the relatively low number of studies.

Saure et al., (2023) [[20](#_ENREF_20)]

Most recently, a Finnish team conducted a large and wide-ranging systematic review and meta-analysis (rated as being of high quality) of gender differences across five autistic characteristic domains in autistic individuals with and without intellectual disability (ID). A total of 79 studies were included considering just under 15,000 autistic people; 28% of whom had an ID.

With respect to studies considering social communication and social interaction, in 39 studies of autistic participants without ID there was an uncertain effect (SMD=-0.17) such that females had *fewer* difficulties than males. However, in 15 studies of autistic people with ID, there was a small effect for females having *more* difficulties in social communication and social interaction than males with ID (SMD=0.20).

For restrictive and repetitive behaviour and interests (RRBI), in 40 studies of autistic people without ID there was a small effect (SMD=-0.23) such that females had *fewer* RRBI than males. For 9 studies considering autistic people with ID, there was an uncertain effect for females having *more* difficulties than males (SMD=-0.11).

Considering sensory processing, there was a small to medium effect (SMD=0.37) in 18 studies such that autistic females without ID had *more* sensory difficulties than autistic males without ID. For autistic people with ID, there was a small effect in the opposite direction such that females had *fewer* difficulties than males in 4 studies (SMD=-0.21).

Analyses found significant group effects for ID status in gender differences for all of these outcomes with the exception of RRBI, for which there was a trend effect (p=0.06).

The reviewers concluded that the female phenotype of autism differs from the male phenotype, and this is moderated by intellectual disability. Indeed, in several studied domains, gender differences were in the opposite direction. Among autistic individuals with ID, females were more severely affected than males.

Limitations of the review include a large heterogeneity, a small number of studies in some categories, and conflicting findings. It is suggested that masking of autistic characteristics may potentially contribute to residual, unexplained heterogeneity.

Studies investigating sex/gender differences in age of autism diagnosis

Two systematic reviews considered whether gender was a possible moderating factor in age of autism diagnosis (see [Table 2.6](#Table2_6)).

Loubersac et al., (2021) [[17](#_ENREF_17)]

A French systematic review (rated as being of medium quality) by Loubersac et al (2021) [[17](#_ENREF_17)] investigated the average of at which the diagnosis of autism is confirmed, and also considered associated moderating/explanatory factors, including age. Fourteen observational cohort studies were identified that investigated the association between gender and age of diagnosis, considering data from over 75,121 autistic people with mean ages of 3 to 9 years.

None of these studies found a significant association with gender. Whilst gender did not appear to be significantly associated with age of diagnosis, the reviewers cautioned that there was a low representation of girls in the study samples, suggesting the possibility of ascertainment and other sampling biases.

The reviewers recommended further studies using large and well-characterized data sets to simultaneously explore clinical and socio-environmental factors involved in early diagnosis.

Table 2.6: Summary of sex/gender differences in age of diagnosis

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Domain of interest | Study authors (year) | Population | Mean age/range | Studies where sex/gender compared | Sex/gender differences | Delayed diagnosis |
| Age of autism diagnosis | | | | | | |
| Average age of diagnosis | Loubersac et al., (2021) [[17](#_ENREF_17)] | Autistic | 3-9 years | K=14 | No difference | NA |
| Average age of diagnosis | Van ‘t Hof et al., (2021) [[21](#_ENREF_21)] | Autistic | 2-48 years | K=56 | In 5/22 studies | Females |

Table 2.7: Summary of sex/gender differences in autistic masking

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Domain of interest | Study authors (year) | Population | Mean age/range | Studies where sex/gender compared | Sex/gender differences | Higher masking |
| Masking | | | | | | |
| Masking, camouflaging, compensating | Cook et al., (2021) [[23](#_ENREF_23)] | Autistic children/adolescents (diagnosed or high autistic characteristics) | 12 years | K=9 | in 7/9 studies | Females |
| Masking, camouflaging, compensating | Cook et al., (2021) [[23](#_ENREF_23)] | Autistic adults (diagnosed or high autistic characteristics) | >18 years | K=9 | in 5/9 studies | Females |
| Passing as non-autistic | Libsack et al., (2021) [[25](#_ENREF_25)] | Autistic people of any age (diagnosed or self-identified) | 24 years | K=19 | Mixed, uncertain | Females |

Note: Masking refers to related concepts of autistic masking, social camouflaging, adaptive morphing, imitating, compensating, and passing as non-autistic

Van ‘t Hof et al., (2021) [[21](#_ENREF_21)]

A systematic review and meta-analysis from The Netherlands by Van ‘t Hof et al [[21](#_ENREF_21)], also rated as being of medium quality, similarly considered age at autism diagnosis in its analyses. The 56 studies identified considered over 120,000 autistic people with a mean age at diagnosis ranging between 2 and 47 years.

Of 22 studies in which gender differences were statistically compared, there was no effect of gender on age at diagnosis in children/adolescents found in 17 studies. In 5 studies, there was a later age at diagnosis for girls than boys. Sex/gender was not included in the meta-analysis as a potential moderating variable as this was not a planned aim of the review.

The authors commented on the lack of consistency in the research base. To better understand variables that may influence age at diagnosis, the reviewers called for research that reports on and evaluates a wide variety of potential moderating factors, and that employs study designs which enable adjustment for covariates.

Studies investigating sex/gender differences in masking of autistic characteristics

Finally, two systematic reviews investigated sex/gender differences in the masking of autistic characteristics, including strategies (of varying intent and effectiveness) including masking, compensating, and passing as non-autistic (see [Table 2.7](#Table2_7)).

These studies vary in terms of the measurement approaches employed to assess masking. Quantitative cross-sectional research into masking has advanced through the use of two broad approaches to measurement: discrepancy metrics and self-report [[75](#_ENREF_75)]. Internal-external discrepancy approaches attempt to quantify the degree to which an individual's autistic social difficulties are masked/camouflaged during an interaction. That is, quantifying the difference between an individual's ‘true’ autistic state (‘internal’ dispositional and/or cognitive autistic status) and their observable behavioural ‘external’ presentation [[74](#_ENREF_74)]. Whereas self-report approaches focus on quantifying an individual's use of self-perceived camouflaging [[23](#_ENREF_23), [77](#_ENREF_77)].

Cook et al., (2021) [[23](#_ENREF_23)]

A systematic review (rated as being of high quality) from a British team [[23](#_ENREF_23)] considered the research into autistic camouflaging/masking in children and adults with either autism diagnoses or high levels of autistic characteristics.

Of studies investigating gender differences in autistic people, 9 included autistic children and adolescents (over 1000), and 9 included adults (over 2,200). The authors note that most studies combined male sex and identifying as male together, and female sex and identifying as female together.

The high majority of studies of young people (7/9) found that girls camouflaged more than boys. Over half (5/9) the studies of adults found that females camouflaged more than males, one of which also found that non-binary gendered people camouflaged more than those identifying as male. The review also reported that higher self-reported masking was associated with poorer mental health outcomes.

Preliminary findings suggest that, although mixed, sex and gender differences exist in camouflaging/masking. However, conclusions are limited by biases in participant recruitment, characterisation and representativeness which suggests that conclusions may not be applied to the autistic community generally.

Libsack et al., (2021) [[25](#_ENREF_25)]

Another systematic review from the United States(of medium quality) considered literature on what they termed ‘passing as non-autistic’ (PAN). PAN was an inclusive term that included any attempt (intentional or otherwise) to minimize, alter, or otherwise change the outward appearance of autistic behaviours, regardless of the perceived level of effectiveness or ineffectiveness attributed to such attempts.

Across 46 studies considering nearly 6,000 autistic people, participants were disproportionately white female adults with average/above average intellectual ability. In 19 studies comparing PAN across genders, 17 (90%) reported findings supporting group differences between genders in behaviours thought to be associated with PAN.

A subset of seven studies directly compared rates of PAN across genders using *discrepancy metrics* (i.e., discrepancy between ‘external’ behavioural presentation and their ‘internal’ autistic characteristics). Five of these studies (4 including adults only) reported greater rates of PAN among autistic females compared to autistic males.

Overall, there was some preliminary evidence that rates of passing as non-autistic may be higher for autistic females than autistic males. However, patterns of effect size and direction of the association were mixed and not broadly interpretable due to the wide variation in participant characteristics, sample size, constructs measured, and study design. In addition, there was high inconsistency in the measurement tools used, a prevalence of overlapping samples, and lack of differentiation between participants’ sex and gender in reporting.

Aotearoa New Zealand research

To support the Living Guideline Group’s consideration of the applicability and generalisability of reviewed international evidence to Aotearoa New Zealand, a search for local research was sought. A wider and more inclusive search strategy was undertaken to identify relevant primary research published in New Zealand since 2004 (see [Appendices A1.2](#A1_2) and [A1.3](#A1_3) for the methodology). No study design limitations were applied, however single case studies and dissertations were excluded. Of the 126 abstracts identified by the search strategy, six were retrieved as full text and four studies were identified of relevant scope to the current review.

In a recently published study, Tanwen Ward and colleagues [[103](#_ENREF_103)] from the University of Waikato conducted a survey of 249 primary school teaching staff in Aotearoa New Zealand. After reading a vignette describing the behaviour of a hypothetical child whose gender was randomly assigned, participants answered questions regarding possible reasons for the behaviour described, including mental health and disability diagnoses. The gender of the described child was not found to have an impact on the likelihood of choosing autism as a potential diagnosis, suggesting that the participants did not make gender‐based assumptions about autistic characteristics. Teachers may have more nuanced understandings of the complexities of autism than expected. However, the authors acknowledge that the way that autism characteristics were presented in this study are unlikely to be representative of the reality of working with autistic students in everyday classrooms. Reassuringly, this study found that when given a description of behaviour that would fulfil all criteria for a formal diagnosis of autism, New Zealand primary school teachers were usually able to identify autism, regardless of the student's gender.

An investigation of the autism diagnostic process in New Zealand was conducted by Autism CRC [[83-85](#_ENREF_83)]. The research involved three online surveys, completed by 458 caregivers of children diagnosed with autism, 70 autistic adults, and 112 clinicians, respectively.

Gender disparities in diagnosis were evident across children and adults. Boys were diagnosed at a younger age on average (6.2 years) compared with girls (7.3 years). The gap between first concerns and diagnosis was also somewhat longer for girls (2.1 years) than boys (1.9 years). Parents of boys were also more satisfied than those of girls with the diagnostic process overall [[84](#_ENREF_84)].

In the study of autistic adults who had received a formal diagnosis within the past 10 years, qualitative data of suggested improvements relevant to gender were reported. These included that clinicians need to be more aware of autism presentation in females, be accessible to people of all ages and genders, and that assessment tools may be less appropriate for females. The researchers argued that these results suggest that many females may be “slipping through the cracks” [[84](#_ENREF_84)]. The sample was under-represented for males (29%), with 63% female, and 9% ‘gender-diverse’[[4]](#footnote-4) [[85](#_ENREF_85)]

In the survey of clinicians, when asked about training preferences, one of the common suggestions was recognising different presentations of autistic characteristics in females [[84](#_ENREF_84)].

Drawing from the research, of four key recommendations made, one explicitly referenced gender:

“Increase awareness of autism among the general public (including parents), educators and clinicians. This should focus on providing education and training about signs and symptoms of autism (across the lifespan and for all genders), implementing Guideline recommendations for the autism diagnostic process (from the time of initial concerns until supports are in place), and effective supports for individuals on the autism spectrum and their families” (p. 11) [[84](#_ENREF_84)].

2.3 Summary and Discussion

Findings are synthesised across studies within the three research areas, with results summarised in [Table 2.5](#Table2_5), [Table 2.6](#Table2_6) and [Table 2.7](#Table2_7).

Note that results synthesised across separate reviews within a research area or outcome domain should not be considered unique findings, as the studies reported for each review may overlap with others. Instead, they are a reflection of the consistency (or lack thereof) of conclusions from reviews of different but overlapping scope.

Some variation between reviews is to be expected given the heterogeneity of measures employed, informants used, and the recruitment and characteristics of the participants, particularly with respect to age.

Sex/gender differences in autistic characteristics

Six studies investigated sex/gender differences in the presentation of autistic characteristics. Key findings are presented in [Table 2.5](#Table2_5).

Results are grouped broadly into outcome domains, and then within each domain into similar sub-categories within which studies are ordered by lower to higher number of included studies for the reported outcome.

For each study/row, whether a significant sex/gender difference was found is indicated, accompanied either by an effect size (based on pooled effect sizes for meta-analyses), or descriptors (for studies synthesised narratively). Where a significant difference is found, the sex/gender experiencing fewer difficulties in that area is shown in the final column.

Colours have been used in the table to visually highlight the degree to which a sex/gender difference is found, ranging from *uncertain*, representing a trend or negligible sex/gender difference (highlighted in orange), a *small* sex/gender difference (highlighted in yellow), or a *small to medium* sex/gender difference (highlighted in green). No effect sizes were found to indicate moderate or large effect sizes.

Social communication and social interaction

Three systematic reviews reported on sex/gender differences within the social communication and/or social interaction domain for autistic people across all age groups. Mahendiran et al (2021) [[18](#_ENREF_18)] found no difference in either social communication or social interaction domains in their review of 8 studies. In the most recent and largest systematic review, Saure and colleagues (2023) [[20](#_ENREF_20)] considered outcomes for autistic people with and without an accompanying intellectual disability (ID). In their meta-analyses, there was a borderline small effect such that males experienced fewer social and communication difficulties in 15 studies of autistic people with ID. In 39 studies of autistic people without ID, there was a non-significant trend favouring females.

These reviews finding no or slight sex/gender differences both employed diagnostic instruments to measure outcomes [[18](#_ENREF_18), [20](#_ENREF_20)]. By contrast, Wood-Downie et al (2021) [[22](#_ENREF_22)] excluded such studies. Instead, eligible studies reported on outcomes representing narrow construct sub-domains. These aimed to capture more subtle and specific sex/gender differences in social interaction and social communication through behavioural exemplars relating to peer relationships, play behaviours, social attention, and social reciprocity assessed through questionnaires, eye-tracking, observational measures, and behavioural tasks. Using this approach, the meta-analysis reported a small to medium effect from 16 studies, with females expressing fewer difficulties than males. The higher abilities of females over males in autistic people mirrored the sex/gender differences found in their non-autistic peers, and in both groups became more evident with increased age. However, social interaction and communication skills improved with age for non-autistic females more than autistic females. This is consistent with the adolescent emergence hypothesis whereby autistic characteristics in females become more apparent in adolescence [[22](#_ENREF_22)].

Taken together these findings suggest that when assessed using current gold-standard diagnostic scales, there is little if any sex/gender differences apparent in the social interaction and communication domain, with a very small advantage for autistic males with an intellectual disability. However, when assessed more subtly across narrow constructs, autistic females demonstrated superior social interaction/communication behaviour compared with autistic males. This more advanced social interaction/communication profile in autistic females mirrored the normative sex/gender differences observed (to a similar effect size) in their non autistic peers [[22](#_ENREF_22)].

It is argued by Wood-Downie and colleagues (2021) [[22](#_ENREF_22)] that the superiority of autistic females’ social interaction/communication abilities over autistic males, whilst being similar to that of non-autistic males, may make their autism less noticeable. In considering (narrow construct) social-communication difficulties in females, it is suggested that practitioners consider normative gender differences; that is, compare females to their same-gender peers rather than to autistic (or nonautistic) males [[22](#_ENREF_22), [104](#_ENREF_104)]. Efforts to consider the characteristics of autistic girls and women in comparison with their non-autistic female peers may improve recognition, referral, and diagnosis of autism.

Restrictive and repetitive behaviours and interests

Four studies reported on restrictive and repetitive behaviours and interests, one on ‘motor stereotypies’/repetitive body movements, two on sensory processing, and the other on RRBI more generally.

Melo et al (2020) [[19](#_ENREF_19)] considered 7 studies investigating ‘motor stereotypies’, finding no sex/gender differences.

A large meta-analysis by Saure et al (2023) [[20](#_ENREF_20)] similarly found no difference in a broad range of RRBI from 9 studies involving autistic people with an intellectual disability. However a small difference was found across 15 studies including autistic people without an ID. For this group, autistic females were found to have fewer restrictive and repetitive behaviours and interests than autistic males.

With respect to sensory processing, a large systematic review considered sensory patterns in autistic people including sensory over-responsivity, under-responsivity, and sensation seeking in 55 studies [[16](#_ENREF_16)]. Sex/gender had a non-significant moderating effect on sensory symptoms in the meta-analysis models.

By contrast, when considering sensory processing difficulties, Saure et al (2023) [[20](#_ENREF_20)] found sex/gender differences varied dependent on whether autism was accompanied by an intellectual disability. In 18 studies of autistic people without ID, there was a small to medium effect for autistic males having fewer sensory difficulties than autistic females. However, in 4 studies of autistic people with ID, there was a small effect in the opposite direction – females were judged as having fewer sensory difficulties than males. It is suggested that previous meta-analyses may have not found sex/gender differences because it depends on whether ID is co-occurring or not.

There is also research suggesting that girls/women may exhibit quantitative and qualitative differences in RRBI than boys/men, which may limit their detection. For example, RRBI observed in autistic girls/women may be more socially acceptable and in alignment with typical sex/gender norms (e.g., celebrities, pop music, fashion, fictional characters, horses, pets), and therefore seem less unusual or autistic. By contrast the RRBI of autistic boys/men tend to be more fixated, and stereotyped (e.g., lining up toys and fascination for parts of objects) [[54](#_ENREF_54), [105](#_ENREF_105), [106](#_ENREF_106)].

Autistic characteristics generally

In a thematic qualitative review of research in autistic adults, Australian researchers Huang et al’s review [[24](#_ENREF_24)] reported contrasting results. Whilst two studies found that women tend to self-report more autistic characteristics then men, two other studies found that women scored similar to men according to clinician-rated diagnostic tools. This review didn’t provide further details of the studies’ populations in order to interpret these findings fully, and the populations of these studies are not comparable. However, findings are consistent with the suggestion that diagnostic tools observed from “the outside” do not necessarily capture the full experience of autism as experienced from “the inside”.

These findings illustrate the complexity of interpreting findings based on different measurement approaches and raise questions about the comparability of the constructs being measured.

Sex/gender differences in age of autism diagnosis

Two systematic reviews [[17](#_ENREF_17), [21](#_ENREF_21)] were identified which estimated the average age at which a diagnosis of autism is confirmed (see [Table 2.6](#Table2_6)). Both considered whether sex/gender was a moderating factor in age of diagnosis.

One review found that no association with sex/gender across 14 studies [[17](#_ENREF_17)]. The other review [[21](#_ENREF_21)] found no difference in 17 of 22 studies, with girls being diagnosed later than boys in 5 studies.

Authors from both reviews called for higher quality research to consider moderating factors including sex/gender. It should be noted that both studies did not include an examination of sex/gender differences as one of their primary aims and were therefore not designed to examine this question.

Sex/gender differences in masking autistic characteristics

It has been hypothesised that autistic girls/women more commonly mask or camouflage their autistic characteristics despite having similar autistic characteristics as boys/men [[74](#_ENREF_74)]. This is an important area of research given that higher self-reported masking has been associated with poorer mental health outcomes [[23](#_ENREF_23)].

Two systematic reviews were relevant (see [Table 2.7](#Table2_7)). One review [[23](#_ENREF_23)] found that girls camouflaged more than boys in 7/9 studies of children and adolescents, and in 5/9 studies of adults. A second review published in the same year [[25](#_ENREF_25)] investigated ‘passing as non-autistic’ (PAN) behaviour. It found sex/gender-based differences in 17/19 studies. However, size and direction of effect size were mixed and not broadly interpretable due to the wide variation in study methodology and sampling. In 7 studies measuring discrepancy of PAN between internal experience and external observations, 5 found greater passing as nonautistic for females compared with males, mostly in adult samples.

Overall, there appears to be preliminary evidence that there may be sex/gender differences in masking such that rates are higher for autistic females than autistic males. However, finding an association between masking and sex/gender may be premature due to inconsistency of measurement approaches and the prevalence of overlapping samples.

The evidence is also limited with respect to biases in participant recruitment and participation. That participants were disproportionately white female adults with average/above average intellectual ability in the larger review [[25](#_ENREF_25)] raises important questions about the generalizability of current empirical knowledge about masking in autism [[25](#_ENREF_25), [81](#_ENREF_81)]. This bias may be an artifact of convenience sampling methods that recruit largely through social media groups (as found in a New Zealand study of autistic adults which included 63% female and 9% ‘gender diverse’ participants [[85](#_ENREF_85)]).

Adding to these limitations of sampling is the preponderance of female-only studies which were not designed to test for sex/gender differences. Instead, these may strengthen the perception of masking as predominantly female strategies. Libsack and colleagues (2021) [[25](#_ENREF_25)] caution that *a priori* assumptions that ‘passing as non-autistic’ (masking) is more common among females “are being made without the support of extensive empirical scrutiny in the current literature” (p. 804).

The limitations of the evidence in this emerging and burgeoning area restrict the ability to make firm conclusions at this time about sex/gender differences in autistic masking.

Aotearoa New Zealand research

An important task of the Living Guideline Group is the development of recommendations based on the international evidence after considering its applicability and generalisability to Aotearoa New Zealand’s people, culture and service context. To supplement members’ lived and professional experiences and judgement, additional relevant primary research conducted in Aotearoa was identified using a wider and more inclusive search strategy to that of the umbrella review. Four studies were identified from a systematic search for primary studies relevant to the current review published since 2004, of any study design, including participants from the New Zealand population [[83-85](#_ENREF_83), [103](#_ENREF_103)].

A vignette study [[103](#_ENREF_103)] assessed primary school teaching staff’s judgements of whether the behaviour of a hypothetical child suggested autism. The child’s sex/gender was randomly assigned, but was not found to affect whether autism was selected as a likely diagnosis.

Three other studies conducted by a research team led by Autism CRC investigated the autism diagnostic process in New Zealand through online surveys of caregivers, autistic adults, and clinicians [[83-85](#_ENREF_83)]. Parents responses suggested that boys were diagnosed at a younger age, and with less delay from raising initial concerns, compared with girls [[84](#_ENREF_84)]. Clinicians recommended more training on how autistic signs may vary across genders [[84](#_ENREF_84)]*.* In a sample over-represented by females and gender-diverse autistic adults, there were calls for greater awareness of sex/gender differences in autism presentation, more appropriate diagnostic tools for females, and a more accessible diagnostic process irrespective of age or gender identity [[85](#_ENREF_85)]. Drawing from all three studies, the research team recommended education programmes and training among the general public, care-givers, educators and clinicians to increase awareness of autistic characteristics as they present across all gender identities and the lifespan [[84](#_ENREF_84)]*.*

These findings are preliminary and based on samples likely to be affected by biases in recruitment and participation. However, they suggest that New Zealanders share similar concerns to those raised in the umbrella review relating to the variable presentation of autism that varies from the predominantly ‘male’ presentation.

Limitations of the umbrella review

The review is limited by the structured approach inherent in its methodology, as well as the quality of the studies appraised.

The current review was initially restricted to English language studies. However, follow-up searching using the same strategy restricted to non-English Journal articles did not identify any eligible reviews. This gives reassurance that the initial language restriction did not affect identification of relevant studies.

The review’s search strategy was very broad and inclusive, using a large list of search terms. The scope of the review was broad and exploratory, and therefore systematic reviews and meta-analyses included in the umbrella review had somewhat different review questions that were nevertheless relevant to the impact of sex/gender on recognition of autism. Study findings were therefore synthesised under different research areas.

Studies were initially selected for appraisal by examining the articles’ abstracts. Therefore, it is possible that some studies were inappropriately excluded prior to examination of the full text. To minimise this possibility, where detail was lacking or ambiguous, papers were retrieved as full text. Supplemental searching, including considering the reference list of all retrieved studies, and narrative reviews retrieved as background material, extended the search catchment, increasing the likelihood of inclusion of eligible secondary studies.

Geographically, most of the primary studies included in the appraised reviews tended to be conducted by researchers in industrialised, developed countries, and featured predominantly white children. The generalisability of the evidence base to the Aotearoa New Zealand population (particularly Māori and Pacific Peoples) and health/disability service context may therefore be limited. Such factors must be considered in implementing the research findings (and this Guideline update) locally. This is particularly needed to honour the Crown’s obligations to Te Tiriti o Waitangi with respect to considering what approaches and resources are needed to achieve equitable health outcomes for Māori[[5]](#footnote-5).

In order to consider the relevance and applicability of the international evidence to Aotearoa’s culture and service systems, relevant New Zealand-based primary research was also identified and reviewed. Criteria were broader in terms of timeframe (2004 – 2023) and study methodology (all designs except single case studies).

It is possible that some excluded studies considered sex/gender differences in their findings of relevance to the current review but were missed as they did not explicitly refer to these in their abstracts. This may be because understanding sex/gender differences was not a key study aim or finding requiring prominence in the abstract. Some studies were also excluded because they considered only one sex/gender (e.g., female autistics only).

Limitations of the evidence base

The evidence base is prone to certain limitations that introduce biases which misrepresent the truth and may lead to distorted results or wrong conclusions. Key limitations of individual reviews and meta-analyses included in this umbrella review have been identified in the syntheses of included papers in the Body of Evidence (see [here](#BodOfEv_NS)).

Common methodological issues included:

* heterogenous and poorly characterised samples
* inconsistency in describing, and failure to differentiate between, biological sex and gender identity in sample characteristics [[25](#_ENREF_25)], a problem that is compounded in reviews attempting to synthesise results across multiple studies
* imprecisely measured sex/gender. For many included reviews, respondents are described as being male or female but it is not known how the questions from the synthesised studies were framed, answered, or coded. This makes interpretation fraught. For example, adults recording their sex/gender as ‘female’ may include cisgender women, transgender people before or following transition, non-binary, genderfluid, or multiple gender identities. This may have a confounding effect, and dilute evidence for gender based autistic characteristics. Given accumulating evidence that being of a gender minority is more common in people on the autism spectrum compared to the broader population [[38](#_ENREF_38)], the impact of such confounders is non-trivial.
* referral and identification biases. For example, some studies were dominated by clinical samples more likely to include people with autistic characteristics that are more obvious (more ‘severe’) [[18](#_ENREF_18)]. Alternatively, some studies relied heavily on convenience or self-selected samples predominantly including people with less obvious autistic characteristics [[19](#_ENREF_19)]. Samples recruited through social media sites have sampling biases in the form of reversed sex ratio, higher employment rates, higher education level, lower fraction of individuals with intellectual disability, and/or later age of diagnosis than expected [[107](#_ENREF_107)]. Such biases impact on the characterisation and representativeness of samples and reduce the generalisability of findings to the general autistic community [[23](#_ENREF_23), [81](#_ENREF_81), [107](#_ENREF_107)].
* small sample sizes and number of studies, particularly reporting on specific domains of autistic characteristics [[17-19](#_ENREF_17), [22](#_ENREF_22)] and representing sub-groups of participants (e.g., adult males, people with intellectual disabilities, those with language difficulties, and non-white ethnic groups) [[20](#_ENREF_20)]
* samples that are either highly dominated by one sex/gender (e.g., males), making them underpowered to detect sex/gender differences for the under-represented sex/gender [[18](#_ENREF_18), [19](#_ENREF_19)], or alternatively included only one sex/gender, precluding examination of sex/gender differences at all [[25](#_ENREF_25)]
* samples that are under-represented for (at least explicitly) autistic individuals who are transgender, non-binary, and/or genderfluid identities
* highly variable and inconsistent definitions of autistic characteristics across different studies, including ‘motor stereotypies’/repetitive body movements [[19](#_ENREF_19)], and concepts of masking [[20](#_ENREF_20), [108](#_ENREF_108)]
* under or non-established validity and reliability of assessment tools employed and high variability in the constructs they are capturing [[19](#_ENREF_19), [25](#_ENREF_25), [108](#_ENREF_108)]
* conflicting sex/gender differences between studies in some domains [[20](#_ENREF_20)]
* residual heterogeneity in meta-analyses, and a lack of consistent measurement of confounding variables that are known to interact with potential sex/gender differences, including IQ, ethnicity, co-occurring conditions, social/cultural environments, type of measures employed, and masking [[18](#_ENREF_18), [20-22](#_ENREF_20)]
* lack of long-term follow-up of the impact of masking on the well-being of autistic individuals.

Future research

Future research needs to address methodological limitations of the evidence relating to sex/gender differences in the presentation of autism.

Examining sex/gender differences in the community is important in understanding whether there are variations between clinical versus community samples [[18](#_ENREF_18)]. To address referral and identification biases, large, population-based, prospective cohort studies with longitudinal follow-up of autistic individuals are needed. These are best able to assess prevalence of autistic characteristics among different gender identities [[19](#_ENREF_19)]. Such samples would permit sex/gender-based comparisons of autistic (identified using active case ascertainment) and non-autistic individuals across a broad range of constructs [[22](#_ENREF_22)].

The use of large and well-characterized data sets would permit investigation of potential moderating variables known to affect the expression of autistic characteristics and to be predictors of early diagnosis [[17](#_ENREF_17)]. Such variables include clinical and socio-environmental factors such as intellectual ability, other co-occurring conditions, socio-economic status, and ethnicity [[18](#_ENREF_18)], and type of measures employed. Assessment of these variables would permit the adjustment for covariates in meta-analysis [[21](#_ENREF_21)].

It is also important to accurately describe study participants’ gender through the application of an inclusive range of identities instead of reporting ambiguous labels such as male and female. This requires two-step measurement of sex assigned at birth and current gender identity.

Research is also needed to ensure diagnostic tools and autism assessment processes do not preference stereotypically male behaviour over more subtle or socially acceptable expressions more common in autistic females.

More consistent use of the same measurement instruments would make synthesis of research more valid. Studies collecting sensory data for autistic females are also needed to investigate whether there are sex/gender differences in sensory patterns [[16](#_ENREF_16)]. Another research gap is the need to clearly and consistently define and measure thoughts and behaviours associated with autistic masking [[23](#_ENREF_23)].

In Aotearoa New Zealand, larger studies with representative samples are needed to further investigate autistic experiences of diagnosis across ages, ethnic groups (particularly Māori and Pacific Peoples), and gender identities. Qualitative research investigating barriers to applying Autism Guideline recommendations relating to diagnosis, and evaluations of professional training interventions in this area, would also be valuable.

2.4 Conclusions

Overview

This systematic umbrella review identified, appraised and synthesised the latest reviews of research investigating sex/gender differences in autistic characteristics. In doing so it updates the evidence base for the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (2022) [1]. This evidence, alongside consideration of relevant New Zealand research, informed the Living Guideline Group’s development of new or revised Recommendations and Good Practice Points as a supplement to the Guideline (see [Part 3](#Part3)).

Sex/gender differences in the presentation of autism are a source of intense and growing research interest over the last decade, and an area which is evolving quickly. A comprehensive search was undertaken of relevant peer-reviewed secondary evidence published since 2018 reporting on at least one unique study. Ten peer reviewed secondary studies were included: five systematic reviews and five meta-analyses. Of the 10, six reviews considered sex/gender-based differences in the presentation of autistic characteristics, two investigated whether sex/gender impacted on the age of autism diagnosis, and two examined differences in the masking of autistic characteristics.

In addition, four primary research studies conducted in New Zealand were identified to provide local context around the applicability of the international evidence. Three were surveys of stakeholders, and one was a vignette study assessing primary school teachers’ judgements of autistic behaviour. These studies complement the international evidence and assist the Living Guideline Group in considering its relevance and applicability to Aotearoa New Zealand.

The reviews appraised were limited to those of moderate to high quality in their methodology and reporting. However, methodological limitations of the primary studies were evident and informed the development of conclusions here.

Key findings

The following key findings and conclusions emerged from the synthesis of 10 systematic reviews and meta-analyses identified.

Social communication and social interaction

The research base is complex and difficult to interpret. Sex/gender differences varied dependent on whether there was accompanying intellectual disability, and how social communication and social interaction was framed and measured.

Autistic females with an intellectual disability (ID) present with slightly more difficulties in the broad **social communication and social interaction** domain (when assessed by diagnostic instruments) compared with autistic males with ID (20 studies). For autistic people without ID, the data is more uncertain but females may have slightly fewer difficulties compared with males without ID (39 studies) [[20](#_ENREF_20)].

When assessed more narrowly and subtly, autistic females presented with fewer difficulties in social communication and social interaction compared with autistic males (16 studies), and more compared to their non-autistic female peers [[22](#_ENREF_22)].

Restrictive and Repetitive Behaviours and Interests (RRBI)

There was no consistent evidence of sex/gender differences in **‘motor** **stereotypies’/repetitive body movements** (7 studies) [[19](#_ENREF_19)].

There were no sex/gender-based difference in **sensory patterns** (sensory over-responsivity, under-responsivity, and sensation seeking) (55 studies) [[16](#_ENREF_16)].

Sex/gender differences emerged in **sensory difficulties** as a function of accompanying intellectual disability. Autistic males without ID presented with slightly fewer **sensory difficulties** than autistic females without ID (18 studies). In autistic people *with ID*, females had fewer sensory difficulties than males (4 studies) [[20](#_ENREF_20)].

Restrictive and Repetitive Behaviours and Interests (**RRBI**) more broadly varied as a function of ID. Autistic females without ID had slightly fewer RRBI than males without ID (40 studies) [[20](#_ENREF_20)]. There was no difference for autistic people *with ID* (9 studies).

Age of diagnosis

Two systematic reviews [[17](#_ENREF_17), [21](#_ENREF_21)] reported uncertain evidence that girls are diagnosed later than boys. However, these studies did not aim to measure sex/gender differences and results may reflect confounders with diagnostic delay relating to characteristic noticeability/severity, age, cognitive abilities, co-occurring conditions, and sampling biases.

Masking

There is preliminary evidence that autistic girls/women more commonly exhibit masking/camouflaging than autistic boys/men (across 12 of 18 studies) [[23](#_ENREF_23)]. However a larger, most recent review concluded that results were mixed and not broadly interpretable with biased samples over-represented for white women of average/above average intellectual ability (19 studies) [[25](#_ENREF_25)].

Limitations in the emerging field of masking research preclude firm conclusions at this time about sex/gender differences in autistic masking.

Aotearoa New Zealand research

In Aotearoa New Zealand, research reflects and enriches the body of international evidence from the umbrella review. Echoing concerns raised by international research is the need for greater awareness of how autistic characteristics may present differently across gender identities (4 studies) [[83-85](#_ENREF_83), [103](#_ENREF_103)]. Researchers have called for greater education and training programmes in the general population level, as well as for educators, health and service providers, and family and whānau, in how to better recognise the diverse ways autism is expressed [[85](#_ENREF_85)]. Given the heterogeneity of autism, it has also been recommended that practitioners select diagnostic tools best suited to the individual being assessed [[83](#_ENREF_83)].

Limitations and future research

A high majority of studies reporting on participant sex/gender in the reviewed literature did not define or differentiate between biological sex and gender, using the two terms interchangeably. This lack of precision hampers our understanding of the how autism variously presents in transgender, non-binary, and/or genderfluid communities.

To build a more comprehensive picture of the many ways autism is expressed in the autistic community, future research needs to have adequate representation of autistic people across gender identities, ages, intellectual abilities, support needs and complexity, other co-occurring conditions, and ethnicity/culture, and the intersection of these identities. With respect to masking, research should explore the context in which such strategies and behaviours develop and are maintained.

Implications for practitioners

Sex/gender differences may vary between autistic people with and without accompanying intellectual disability. Evidence suggests that in the absence of ID, when compared with autistic males, autistic females may present with more sensory difficulties, and fewer RRBI [[20](#_ENREF_20)]. However, both differences appear to be slight.

When considering the possibility of referral or diagnosis for autism, practitioners should be aware of the diversity of presentations of autism and consider the possibility of sex/gender-based differences in autistic characteristics.

In assessment for autism, individuals’ presenting characteristics should be compared with reference to those of non-autistic peers of the same sex/gender and intellectual abilities.

The scope of diagnostic instruments may contribute to an under-recognition of autism in females. Autistic girls and women appear to be more likely to show nuanced social-communication differences that might not be well captured by standardised instruments or observation [[22](#_ENREF_22), [55](#_ENREF_55)]. Restrictive and repetitive behaviours and interests (RRBI) observed in autistic girls/women may present in ways that are more socially acceptable and align with typical sex/gender norms. These differences may be a barrier to recognition of autism.

In responding to the dominance of young boys in autism research and the development of assessment tools, there have been efforts to characterise a ‘female phenotype of autism’ to balance an historically male-based lens on autism [[109](#_ENREF_109), [110](#_ENREF_110)]. Ironically, efforts to challenge one sex/gender stereotype about autism could instead lead to another. Presenting masking as a ‘female’ strategy associated with ‘female autism’ could make it harder for people who do not fit such a profile to receive a diagnosis and support [[78](#_ENREF_78)]. Researchers and practitioners should be cautious not to reinforce a binary view of gender. This is particularly important given that there is accumulating evidence that transgender, non-binary and genderfluid individuals are more common in the autistic community than in the general population [[37-39](#_ENREF_37)].

When assessing characteristics for autism, clinicians and practitioners should be aware that diagnostic characteristics of autism may present differently to stereotypically male presentation, particularly for individuals who are (cisgender) female/girls/women, transgender, non-binary, and/or genderfluid.

Autistic masking involves the use of behavioural and cognitive strategies to adapt to, or cope within, a predominately non-autistic social world. There is preliminary evidence that masking may be more common in females. However, the limitations of the evidence in this emerging area restrict the ability to make firm conclusions. Higher self-reported masking has been associated with poorer mental health.

Masking of autistic characteristics can occur regardless of age or gender identity. Support goals should be consistent with creating an environment where autistic people can be safely and authentically autistic.

Part 3: Recommendation development

The Living Guideline Group ([LGG](#LGG)) were tasked with considering the systematically reviewed evidence reported in [Part 2](#Part2). Specifically, whether the updated body of evidence required revisions to the Guideline’s existing Recommendations and Good Practice Points (GPP) as well as the development of new ones.

The text and graded ‘strength of evidence’ (see Appendix 1, [Table A1.2](#TableA1_2)) of any potential new Recommendations were considered at an all-day meeting. The LGG’s decisions are presented below and summarised in the [Summary Table](#SummTable). Where considered helpful, these decisions are accompanied by additional explanatory text, and/or with a brief rationale which highlights any particular issues that the LGG took into account in their deliberations.

Decisions of the Living Guideline Group

Preamble

A systematic review was conducted to inform the LGG’s revision and development of recommendations to update the Guideline relating to how an autistic person’s sex/gender may affect their assessment for a diagnosis of autism. Specifically, whether there are sex/gender-based differences in the presentation of characteristics of autism relevant to clinical diagnosis (i.e., ‘core characteristics’).

Sex/gender differences in the presentation of autism is a highly researched and evolving area. Whilst the terms are often used interchangeably, gender refers to an individual’s social and personal identity and/or gender expression [[36](#_ENREF_36)], whereas ‘sex’ is based on a person's sex characteristics, and is typically assigned as observed and recorded in infancy. Sex can be changed to align with a person’s gender identity.

Autism prevalence internationally has been estimated as having a 4:1 male to female ratio, though this is highly variable across countries and ascertainment methods. There is evidence that females have historically been under-diagnosed in the community across their lifespan due to a range of biases reflecting sociocultural norms. These may be due to expectations around autism being a mainly male condition, expressed in stereotypically male ways, and assessed using tools developed mainly with male participants.

There is also a growing awareness of the phenomena of autistic masking and how it may make autism diagnosis harder. Autistic masking involves the use of behaviours and strategies to adapt to, or cope within, a largely non-autistic social world. It is an umbrella term for a range of processes including social camouflaging, passing as non-autistic (PAN), adaptive morphing, mimicry, imitation, compensation, accommodation, and assimilation.

Researchers and practitioners should be cautious to not reinforce a binary view of gender, particularly given there is accumulating evidence that transgender, non-binary and genderfluid individuals are more common in the autistic community than in the general population.

New Recommendations and Good Practice Points

**New Recommendation 1.2.14a**: When considering referral or diagnosis for autism, practitioners should be aware of the diversity of presentations of autism and consider potential gender-based differences in autistic characteristics. **(Grade B)**

**New Good Practice Point 1.2.14b**: When considering referral or diagnosis for autism, an individual’s presentation should be compared to those of non-autistic peers of the same gender and intellectual abilities.

In assessment, clinicians and practitioners should be aware that diagnostic characteristics of autism may present differently to stereotypically male presentation, particularly for individuals who are (cisgender) female/girls/women, transgender, non-binary, and/or genderfluid.

* ***Rationale***: When assessed more subtly across narrow constructs, autistic females demonstrated superior social interaction/communication behaviour compared with autistic males. This more advanced social interaction/communication profile in autistic females mirrors the normative sex/gender differences observed (to a similar extent) in their non autistic peers [[22](#_ENREF_22)].
* ***Additional text:*** There is a lack of research investigating how transgender, non-binary, and/or genderfluid may differ in their presentation of autism to cisgendered people. In the absence of established norms for autistic presentation across gender minority identities, comparisons will rely on practitioner experience and expertise.

**New Recommendation 1.2.14c**: Masking of autistic characteristics can occur regardless of age or gender identity. Clinicians and practitioners should consider the possible presence of autistic masking. **(Grade A)**

* ***Additional text***: There is preliminary evidence that masking may be more common in females. However, the limitations of the evidence in this emerging area restrict the ability to make firm conclusions.

**Good Practice Point 1.2.14d**: An autistic-friendly environment for assessment should be provided where the autistic person can be safely and authentically autistic.

* ***Additional text***: Cross reference to GPP 4.3.13 relating to autistic-friendly ethical practice.

**New Recommendation 3.4.4a**: Masking of autistic characteristics can occur regardless of age or gender identity. Educators and learning support practitioners should consider the possible presence of autistic masking. **(Grade A)**

* ***Additional text***: There is preliminary evidence that masking may be more common in females. However, the limitations of the evidence in this emerging area restrict the ability to make firm conclusions.

**Good Practice Point 3.4.4b**: An autistic-friendly environment should be provided in classrooms and schools where the autistic learner can be safely and authentically autistic.

* ***Additional text***: The Ministry of Education provides resources that advise on ways to ensure classrooms are inclusive for all learners[[6]](#footnote-6).

**New Recommendation 5.2.9a**: Masking of autistic characteristics can occur regardless of age or gender identity. **(Grade A)**

* ***Additional text***: There is preliminary evidence that masking may be more common in females. However, the limitations of the evidence in this emerging area restrict the ability to make firm conclusions.

**Good Practice Point 5.2.9b**: An autistic-friendly environment should be provided in the community where autistic people can be safely and authentically autistic.

* ***Additional text***: Cross reference to GPP 4.3.13 relating to autistic-friendly ethical practice.

The [Summary Table](#SummTable) of the [Executive Summary](#ExecSumm) summarises the new Recommendations and Good Practice Points.

Appendix 1: Methods

A1.1 Acknowledgements

Living Guideline Manager

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Living Guideline Group (LGG)

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**Larah van der Meer**, Autism researcher; Adjunct Research Fellow at Victoria University, and National Research and Advocacy Manager at Autism New Zealand (did not attend the meeting)

Ex-officio LGG members

Ex-officio members include the programme funders and sponsors.

**Donna Caddie**, Manager Strategy and Budget, Te Pae Aronui, Ministry of Education of New Zealand.

**Helen Hayes**, Portfolio Manager; Whaikaha – Ministry of Disabled People of New Zealand

**Nadine Rohe** (Manager Learning Support Practice, Te Pae Aronui, Ministry of Education of New Zealand) attended the meeting as an observer

Other support

The Ministry of Education Library provided access to databases and assisted with inter-loan retrieval.

The author acknowledges the helpful feedback received during preparation and consultation for this paper. In particular, Dr Ruth Monk provided valuable insights into discussions about autistic preferences and perspectives relating to autistic masking.

Gender Minorities Aotearoa provided detailed and extremely helpful feedback around terminology and concepts that led to expanding the Glossary and clarifying use of terms.

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Declarations of interest

None

A1.2 Search strategy

Search strategies were limited to publications from January 1 2018 onwards. Database searches were conducted between 9 and 13 July 2023. Full search strategies are available upon request.

Databases

Bibliographic, health technology assessment and guideline databases were included in the search strategy, listed below.

* Medline (EBSCO-Host)
* Cinahl (EBSCO-Host)
* PsycInfo (EBSCO-Host)
* EMBASE (OVID)
* Cochrane Database (Cochrane Library website)

Search terms

A combination of search terms were developed and adapted for different databases. Searches were initially limited to those: published in the English language, involving human participants, and published in peer-reviewed Journals since January 2018. Dissertations were also excluded.

Original searches were initially conducted between 9 – 13 July 2023 and were re-run on 18 October 2023 to update publications in the intervening period. Reference lists of relevant systematic reviews and included studies were also manually checked.

Duplicates were removed iteratively using EndNote 20's duplication identification strategy and manually (n=57). This left a total of 1160 unique potentially eligible abstracts (see [Figure 1](#fig1)).

Hand searching of journals and contacting of authors for unpublished research were not undertaken. Authors were contacted for clarification where needed.

The following illustrative search syntax is offered below:

|  |  |
| --- | --- |
| S9 | (S5 AND S6 AND S7 ) NOT (PT (letter OR editorial OR comment OR case reports OR historical article OR published erratum OR retracted publication OR retraction of publication) ) NOT TI (protocol OR protocols OR withdrawn OR reply or books or chapters or conference abstract ) NOT AB (atrial septal defect OR acute stress disorder OR adult spinal deformity OR adjacent segment degeneration ) |
| S8 | S5 AND S6 AND S7 |
| S7 | (S1 OR S2 ) OR (S3 AND S4 ) |
| S6 | TI (sex or gender or female or females or girl or girls or woman or women or sex/gender ) OR AB ( sex or gender or female or females or girl or girls or woman or women or sex/gender ) OR SU (sex or gender or female or females or girl or girls or woman or women or sex/gender ) |
| S5 | TI (autism or autistic or asperger or aspergers OR ASD ) OR AB (autism or autistic or asperger or aspergers OR ASD ) OR SU (autism or autistic or asperger or aspergers OR ASD ) |
| S4 | TI (study selection OR selection criteria OR eligibility criteria OR inclusion criteria OR exclusion criteria) OR AB (study selection OR selection criteria OR eligibility criteria OR inclusion criteria OR exclusion criteria ) |
| S3 | TI (search\* OR medline OR pubmed OR embase OR CINAHL OR psycinfo OR cochrane ) OR AB (search\* OR medline OR pubmed OR embase OR CINAHL OR psycinfo OR cochrane ) |
| S2 | TI (systematic overview\*) OR TI (Cochrane review\*) OR TI (systematic review\*) OR TI (scoping review) OR TI (scoping literature review) OR TI (mapping review) OR TI (umbrella review\*) OR TI (review of reviews) OR TI (overview of reviews) OR TI (meta-review) OR TI (integrative review) OR TI (integrated review) OR TI (integrative overview) OR TI (meta-synthesis) OR TI (metasynthesis) OR TI (quantitative review) OR TI (quantitative synthesis) OR TI (research synthesis) OR TI (meta-ethnography) OR TI (systematic literature search) OR TI (meta-analyses) OR TI (metaanalyses) OR TI (meta-analysis) OR TI (metaanalysis) OR TI (meta-analytic review) OR TI (meta-analytical review) OR PT (meta-analysis) OR PT (systematic review) |
| S1 | TI systematic\* AND TI review |

To check whether the English language exclusion was likely to have missed eligible articles, a follow-up search was undertaken on 18 October 2023 which included all languages excepting those published in English.

The search strategy identified 42 articles not published in English. None of these met select criteria for the current overview of systematic reviews.

Grey literature

The following websites were searched to identify relevant guidelines or systematic reviews

* https://www.cochranelibrary.com/?contentLanguage=en
* https://g-i-n.net/international-guidelines-library
* https://sites.bvsalud.org/bigg/en/biblio/
* https://www.evidence.nhs.uk/search?q=guidelines
* https://www.ncbi.nlm.nih.gov/pmc/about/intro/
* https://www.sign.ac.uk/our-guidelines/
* https://www.uspreventiveservicestaskforce.org
* https://www.who.int/publications/who-guidelines
* https://www.tripdatabase.com
* https://www.autismcrc.com.au

New Zealand-based qualitative research

To consider the relevance and applicability of the international systematic review of effectiveness to Aotearoa’s cultural and service context, a second search was conducted on 18 October 2023. Eligible studies included New Zealand-based participants involved in the recognition, assessment or diagnosis of autism, which considered sex/gender differences in autistic characteristics in their scope. This material was narratively summarised as background material and was not critically appraised.

The search strategy employed for the umbrella review was adapted to remove the methodology filters, and to add a search for ‘New Zealand’, ‘Maori’, or ‘Aotearoa’ in any search field. Te Aka Māori Dictionary (https://maoridictionary.co.nz) was used to identify Māori language translations for English words relating to sex and gender to be added as search terms (see Glossary for English translations). The search strategy is presented below.

|  |  |
| --- | --- |
| S5 | AF (New Zealand OR Maori OR Aotearoa) AND S4 |
| S4 | S3 NOT PT (letter OR editorial OR comment) OR (case AND reports) OR (historical AND article) OR (published AND erratum) OR (retracted AND publication) OR (retraction AND publication)  NOT TI (protocol OR protocols OR withdrawn OR reply OR books OR chapters OR (conference AND abstract)  NOT AB (atrial AND septal AND defect) OR (acute AND stress AND disorder) OR (adult AND spinal AND deformity) OR (adjacent AND segment AND degeneration) |
| S3 | S1 AND S2 |
| S2 | TI (sex OR gender OR female OR females OR girl OR girls OR woman OR women OR sex/gender) OR AB (sex OR gender OR female OR females OR girl OR girls OR woman OR women OR sex/gender) OR (wahine OR taitamāhinetanga OR kōtiro OR tamāhine OR wahine OR hengahenga OR hine OR kōhine OR tamawahine OR māitiiti OR tamaiti OR tama OR tamatāne OR tānetanga OR taihema taketake OR uha OR uwha) OR AB (wahine OR taitamāhinetanga OR kōtiro OR tamāhine OR wahine OR hengahenga OR hine OR kōhine OR tamawahine OR māitiiti OR tamaiti OR tama OR tamatāne OR tānetanga OR taihema taketake OR uha OR uwha ) |
| S1 | TI (autism OR autistic\* OR asperger OR aspergers OR ASD) OR AB (autism OR autistic\* OR asperger OR aspergers OR ASD) |

Databases included Medline, Cinahl, PsycInfo, Australia/New Zealand Reference Centre Plus (searched through EBSCO-Host) and Embase (searched through Ovid, omitting S4 limiters).

These searches were limited to English language, 2004-current, human participants, and studies published in academic journals. Hand searching of journals was not undertaken.

Excluded were case studies and autobiographical accounts. Academic dissertations at Masters or PhD level published between 2004 and 2023 were searched using the following search strategy:

(autism or autistic or ASD or asperger or aspergers) AND (sex OR gender OR female OR females OR girl OR girls OR woman OR women OR sex/gender)

This strategy identified 126 unique abstracts, four of which met criteria for inclusion.

A1.3 Study selection

A single autism researcher (the author) performed study selection, data extraction, critical appraisal, and synthesis. The researcher has conducted 16 systematic reviews in autism.

Levels of evidence

Research study designs are broadly associated with particular methodological strengths and limitations in terms of how bias is minimised. This allows studies to be assigned a “level of evidence” within an evidence hierarchy [[94](#_ENREF_94)], so as to rank them in terms of quality from most robust (level I) to least (level IV). Level I evidence is represented by systematic reviews and meta analyses including at least one level II study.

Consistent with the evidence-based practice model, research questions are most robustly answered using study designs that appear higher in the evidence hierarchy and a lower risk of bias. Only in their absence is lower order evidence included.

Using this principle, recently published systematic reviews considering studies within the broader scope can be considered ‘best evidence’. In this ‘umbrella review’ of systematic reviews and meta analyses, primary studies were not individually appraised.

Definition of systematic reviews

In the current review, only systematic reviews published in or since 2018 were considered.

Eligible systematic reviews (whether including a meta-analysis or narrative synthesis) needed to meet the following criteria: (1) include a clear statement of the purpose of the review; (2) describe the search strategy (including key search terms, multiple relevant databases, specification of search dates); (3) indicate the criteria used to select studies for inclusion; (4) and present findings relevant to the scope of the current systematic review.

Study designs considered for New Zealand based research

New Zealand-based studies considered in [Section 1.3](#NZResearch) were identified to provide background information about the local cultural and service context to the international umbrella review

To answer this research question, primary studies employing any study design and published in or since 2004 were eligible, including those using qualitative analysis. It is understood that qualitative research is best able to describe autistic experiences including relevance, applicability, acceptability, and feasibility, including preferences and values. Other selection criteria were the same as for the umbrella review.

A1.4 Data extraction

Study characteristics were extracted for each of the appraised studies and entered into Evidence tables (see [Appendix 3](#App3)). Key features recorded for primary studies included:

* citation
* country (of all, most or first author)
* type of review, study quality (see Section A1.5 below)
* aim of the review
* search strategy (databases searched, date range, process)
* selection criteria
* review methodology
* critical appraisal tool used
* meta analysis method, where relevant
* number of included studies, sex/gender and age statistics
* study designs, study quality, publication bias, where appraised
* key findings
* author conclusions
* comments/notes from (unbrella) reviewer

Only relevant findings (relating to sex/gender differences) were reported.

A1.5 Critical appraisal

Studies were assessed for study quality using the Joanna Briggs Institute (JBI) checklist for systematic reviews and research synthesis [[91](#_ENREF_91)]. Each of the 11 questions posed in the checklist can be scored as being ‘met’, ‘not met’, ‘unclear’ (or rarely, ‘not applicable’). Items are presented in [Table A1.1](#TableA1_1).

Applying a strategy used for an autism umbrella review [[111](#_ENREF_111)], each item was scored 1 if “met” with scores summed to categorise study quality as follows: low (score 0-5), medium (score 6-8), or high (score 9–11). Reviews rated as being of low quality (scoring under 6) were excluded.

Table A1.1: Critical appraisal checklist for systematic reviews and research synthesis

|  |
| --- |
| Is the review question clearly and explicitly stated? |
| Were the inclusion criteria appropriate for the review question? |
| Was the search strategy appropriate? |
| Were the sources and resources used to search for studies adequate? |
| Were the criteria for appraising studies appropriate? |
| Was critical appraisal conducted by two or more reviewers independently? |
| Were there methods to minimize errors in data extraction? |
| Were the methods used to combine studies appropriate? |
| Was the likelihood of publication bias assessed? |
| Were recommendations for policy and/or practice supported by the reported data? |
| Were the specific directives for new research appropriate? |

**Source**: Joanna Briggs Institute [[91](#_ENREF_91)]

A1.6 Preparing Recommendations

A meeting was held on 2 February 2024 where the Living Guideline Group considered the findings of the current systematic review. Using their collective professional judgement and experience, the LGG discussed the body of evidence with respect to the research question and the applicability of the evidence within Aotearoa New Zealand. They considered (any) existing affected Recommendations and Good Practice Points from the Guideline [1] and the development of new ones.

Developing Recommendations involves consideration of the whole evidence base for the research question. The quality and consistency of the evidence and the practice implications within an Aotearoa New Zealand context is weighed up by all the LGG members.

Each Recommendation is assigned a grade to indicate the overall ‘strength of the evidence’ upon which it is based. The grades of Recommendations used by the LGG, and also used in the Guideline [1], are presented in [Table A1.2.](#TableA1_2)

Strength of the body of evidence is determined across three domains [[94](#_ENREF_94)]:

* quality (the extent to which bias was minimised as determined by study design and the conduct of the study)
* quantity (magnitude of effect, numbers of studies, sample size or power)
* consistency (the extent to which similar findings are reported.

The wording of Recommendations and Good Practice Points, and the evidence grade, is determined by the LGG through discussion and group consensus during the meeting.

Table A1.2: Grades for Recommendations

|  |  |
| --- | --- |
| Recommendations | Grade |
| The Recommendation is supported by good evidence (based on a number of studies that are valid, consistent, applicable and clinically relevant) | A |
| The Recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence) | B |
| The Recommendation is supported by international expert opinion | C |
| The evidence is insufficient, evidence is lacking, of poor quality or opinions conflicting, the balance of benefits and harms cannot be determined | I |
| Good practice point | Grade |
| Where a Recommendation is based on the clinical and educational experiences of members of the Living Guideline Group, or feedback from consultation within Aotearoa New Zealand, it is a Good Practice Point. | ✓ |

A1.7 Consultation

Seeking comments from stakeholders is vital for peer-review and quality assurance processes in developing the report. In a focused consultation, 12 key stakeholder organisations/individuals were approached for feedback on a late draft of the report. Particular attention was sought regarding the relevance of the report to Aotearoa New Zealand’s services and needs, clarity and ease of use of the report, and implementability of the revised or new Recommendations and Good Practice Points.

Seven of 12 organisations responded to the invitation, with feedback being largely very positive. The Autism/Takiwātanga Living Guideline Manager (INSiGHT Research) collated feedback and drafted revisions for the Living Guideline Group to consider.

Suggestions identified in the consultation led to several improvements to the final report.

INSIGHT Research and the LGG are grateful to those individuals and organisations who participated in the consultation process.

Appendix 2: Abbreviations and glossaries

A2.1 Abbreviations and acronyms

Miscellaneous Terms

ADHD attention deficit hyperactivity disorder

AFAB assigned female at birth

AMAB assigned male at birth

ASD Autism Spectrum Disorder

*d* (Cohen’s) d, an indicator of effect size

DQ disability quotient

GPP Good Practice Point

ID intellectual disability

IQ intelligence quotient

INSIGHT Research INdependent Specialist in Guidelines & Health Technology Research

JBI Joanna Briggs Institute

*k* number of studies

LGG Living Guideline Group

M mean

NA not applicable

*N (or n)* number (usually, sample size)

NHMRC National Health and Medical Research Council (Australia)

NR not reported

NZ New Zealand/Aotearoa

PAN passing as non-autistic

PDD Pervasive Developmental Disorder

PDD-NOS Pervasive Developmental Disorder – Not Otherwise Specified

PICO Participants, Intervention, Comparator, Outcomes

PICo Population, phenomena of Interest, Context

RRBI restrictive and repetitive behaviour and interests

SD standard deviations

SMD standardised mean difference

SOR sensory over-responsivity

SUR sensory under-responsivity

TD typically developing

UK United Kingdom

USA United States of America

Tests, scales and measures

ADI-R Autism Diagnostic Interview-Revised

CAT-Q Camouflaging Autistic Traits Questionnaire

DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders - IV (text revision)

DSM5 Diagnostic and Statistical Manual of Mental Disorders – 5th edition

GRADE Grading of Recommendations, Assessment, Development and Evaluations

MMAT Mixed Methods Appraisal Tool

NOS Newcastle Ottawa Scale

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

SRS Social Responsiveness Scale

STROBE Strengthening the Reporting of Observational Studies in Epidemiology

Databases

CINAHL Cumulative Index to Nursing and Allied Health Literature

EMBASE Excepta Medica Database

Medline Medical Literature Analysis and Retrieval System Online

PsycINFO Psychology Information Database

A2.2 Glossary of terms

**Agender**

someone who feels neutral in their gender, or an absence of gender, or who rejects the influence of gender on their person.

**Assigned female at birth (AFAB)**

person whose sex at birth was recorded or assigned as female. Note: intersex people are often re-assigned a sex after birth, sometimes multiple times. Be cautious applying this framework to intersex people.

**Assigned male at birth (AMAB)**

person whose sex at birth was recorded or assigned as male. Note: intersex people are often re-assigned a sex after birth, sometimes multiple times. Be cautious applying this framework to intersex people.

**Bias**

Bias is a systematic deviation of a measurement from the ‘true’ value leading to either an over- or under-estimation of the treatment effect. Bias can originate from many different sources, such as allocation of patients, measurement, interpretation, publication and review of data.

**Bigender**

A non-binary gender identity that indicates having two different genders. They could be both male or female, or be any other two genders. This term is different from and should not be confused with the term Two-Spirit – a gender identity specific to certain Native American and First Nations cultures.

**Case series**

Case series are collections of individual case reports, which may occur within a fairly short period of time. Cases consist of either only the exposed people with the outcomes, or people with the outcome regardless of the exposure. In neither of these examples can the risk for the outcome be determined

**Cisgender (cis, or cissexual)**

refers to a person whose gender is the same as the sex recorded at their birth **Cross-sectional study**

A study that examines the relationship between exposures (e.g., risk factor) and outcomes (e.g., disease), as they exist in a defined population, at a particular time. A group of people are assessed at a particular point (or cross-section) in time and the data collected on outcomes relate to that point in time; i.e., proportion of people with asthma in October 2022. This type of study is useful for hypothesis-generation, to identify whether a risk factor is associated with a certain type of outcome, but more often than not (except when the exposure and outcome are stable; e.g., genetic mutation and certain clinical symptoms) the causal link cannot be proven unless a time dimension is included.

**Effect size**

A quantitative measure of the strength of a phenomenon, a standardized measure of the size of the difference between two groups. The effect sizes can be interpreted in accordance with common guidelines for interventions in the behavioural sciences where effect sizes of up to 0.2 are considered small, those around 0.5 are moderate, and those at 0.8 and above are large [[112](#_ENREF_112)].

**Gender/gender identity**

refers to a person’s social and personal identity as male, female, or another gender or genders that may be non-binary. Gender may include gender identity and/or gender expression. A person’s current gender may differ from the sex recorded at their birth and may differ from what is indicated on their current legal documents. A person’s gender may change over time. Some people may not identify with any gender

**Gender diverse**

Umbrella term used by some people to define people outside the gender binary (including Stats NZ). However, Gender Minorities Aotearoa define gender diverse as referring to all gender variety, including cisgender people. Given the varying understandings in the community, and that it is often used euphemistically, this term is avoided in the current review except where citing the use of the term by researchers (where it is placed in scare quotes).

**Gender expression/presentation**

refers to a person’s presentation of gender through physical appearance including dress, hairstyles, accessories, cosmetics, mannerisms, speech, behavioural patterns, body shape, names, and personal references. May not align with a person’s gender identity (e.g., when cross-dressing).

**Gender identity**

refers to a person’s internal and individual experience of gender

**Gender dysphoria**

Gender dysphoria is a clinical diagnostic term referring to dissonance between one’s assigned gender and/or body, and their personal sense of self. As diagnostic category, it is still often seen as a pathology. “Gender Dysphoria” is now being moved away from, in favour of more broad recognition of ‘gender inconguence’.

**Genderfluid**

Genderfluid can refer to a person whose gender changes over time, often between multiple binary or non-binary genders. (Note 1: As a separate concept, ‘gender fluidity’ can refer to any changeableness around gender, gender transition and prevalence of transgender people in society. This use should not be confused with the first definition for genderfluid). (Note 2: Some individuals choose to identify as genderfluid as distinct from transgender. Gender Minorities Aotearoa consider transgender to be the counterpart to cisgender, as its linguistic opposite, and that it refers to all gender minorities, including genderfluid. In the current paper, genderfluid is listed separately from transgender in order to be as inclusive as possible).

**Gender Minorities**

people whose gender are seen as separate from the social majority of cisgendered people

**Generalisability**

Applicability of the results to other populations.

Grading of Recommendations, Assessment, Development and Evaluations (GRADE)

GRADE (Grading of Recommendations, Assessment, Development and Evaluations) [[113](#_ENREF_113)] is a transparent framework for developing and presenting summaries of evidence and provides a systematic approach for making clinical practice recommendations. An effect size is estimated (from a systematic review and/or meta-analysis) and then the quality of evidence is estimated for each outcome. An overall GRADE quality rating can be applied to a body of evidence across outcomes, usually by taking the lowest quality of evidence from all of the outcomes that are critical to decision making.

GRADE has four levels of evidence – also known as certainty in evidence or quality of evidence: very low, low, moderate, and high. Evidence from randomised controlled trials starts at high quality and, because of residual confounding, evidence that includes observational data starts at low quality.

The certainty in the evidence can be decreased based on the following methodological factors: risk of bias, imprecision, inconsistency, indirectness, and publication bias. In contrast, the certainty in the evidence can be increased based on a large magnitude of effect, and dose-response gradient.

**Intersex**

an umbrella term used to describe a wide range of variations in sex characteristics. When an intersex infant is born with ambiguous external genitalia, parents and clinicians typically assign them a binary sex and perform surgical operations to conform the infant’s body to that assignment. Many intersex variations are not visible or detected at birth and many people may not be aware they have an intersex variation until later in life (for example, in puberty). Some people may identify as intersex, while others may see their intersex variation more as part of their medical history, rather than their identity.

**Level of evidence**

Levels within a hierarchy of study evidence that indicates the degree to which bias has been eliminated in the study design.

**Mean**

Calculated by adding all the individual values in the group and dividing by the number of values in the group.

**Meta analysis**

Meta-analysis is the use of statistical techniques to combine and summarize the results of multiple studies; they may or may be contained within a systematic review. By combining data from several studies, meta-analyses can provide more precise estimates of the effects of health care than those derived from the individual studies.

**Neurodiversity**

An approach to learning and disability which suggests that diverse neurological conditions appear as a result of normal variation in the human genome. This term was coined in the late 1990s as a challenge to prevailing views of neurological diversity as inherently pathological, and it asserts that neurological differences should be recognised and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status.

**Non-binary (nonbinary)**

An umbrella term for all genders other than just female/woman/girl or male/man/boy. Use as an adjective (e.g., ‘Alex is non-binary’). (Note: Some individuals choose to identify as non-binary as distinct from transgender. Gender Minorities Aotearoa consider transgender to be the counterpart to cisgender, as its linguistic opposite, and that it refers to all gender minorities, including non-binary. In the current paper, non-binary is listed separately from transgender in order to be as inclusive as possible).

**Observational studies**

Also known as epidemiological studies. These are usually undertaken by investigators who are not involved in the clinical care of the patients being studied, and who are not using the technology under investigation. Distinct from experimental studies.

**PICO framework**

A mnemonic used to frame a research question’s parameters which is useful for developing search strategies and selection criteria; particularly valuable for systematic reviews investigating intervention effectiveness. The letters stand for

**P** – Participant or population

**I** – Intervention

**C** – Comparison, control or comparator

**O** – Outcome(s)

T is sometimes added to represent dates of population or duration of intervention.

**PICo framework (an alternative to PICO)**

A mnemonic used to frame a research question’s parameters which is useful for developing search strategies and selection criteria in systematic reviews. This framework is suggested for research questions in which the phenomena of interest represent the outcome and is particularly valuable for syntheses of qualitative phenomena including lived experience. The letters stand for:

**P** – Participant or population

**I** – phenomena of Interest

**Co** – Context

**Power**

The probability that a statistical test or study will detect a defined pattern in data and declare the extent of the pattern as showing statistical significance.

**Prevalence**

A measure of the proportion of people in a population who have some attribute or disease at a given point in time or during some time period.

**Pseudo-randomised controlled trial**

As for a randomised controlled trial except that a pseudo-random method (such as alternate allocation, days of the week, date of birth, or odd-even medical record numbers) is described for allocating individuals into treatment or control group conditions. The outcomes from each group are compared. Sometimes known as quasi-randomised controlled trials.

**Quality of evidence**

Degree to which bias has been prevented through the design and conduct of research from which evidence is derived.

**Randomised controlled trial (RCT)**

An experiment in which a unit (e.g., people, or a cluster of people) are allocated using a fully random mechanism (such as a coin toss, random number table, computer-generated random numbers) into either the intervention condition (e.g., preventive or therapeutic procedure, manoeuvre, or treatment) or a control comparison condition (e.g., placebo, usual care, alternative treatment). The outcomes from each group are compared. Conditions are run in parallel.

**Secondary study**

An analysis or synthesis of research data reported elsewhere, including systematic reviews, meta-analyses and guidelines.

**Selection bias**

Error due to systematic differences in characteristics between those who are selected for inclusion in a study and those who are not (or between those compared within a study and those who are not).

**Sex**

is based on a person’s sex characteristics, such as their chromosomes, hormones, and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, a person’s sex can change over the course of their lifetime and may differ from their recorded at birth.

**Sex characteristics**

refer to each person’s physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty

**Strength of evidence**

The strength of evidence for an intervention effect includes the level (type of studies), quality (how well the studies were designed and performed to eliminate bias) and statistical precision (p-value and confidence interval).

**Systematic review (SR)**

A systematic review attempts to collate all relevant evidence that fits pre-specified eligibility criteria to answer a specific research question. It uses explicit, systematic methods to minimize bias in the identification, selection, synthesis, and summary of studies. The key characteristics of a systematic review are (a) a clearly stated set of objectives with an explicit, reproducible methodology; (b) a systematic search that attempts to identify all studies that would meet the eligibility criteria; (c) an assessment of the validity of the findings of the included studies (e.g., assessment of risk of bias and confidence in cumulative estimates); and (d) systematic presentation, and synthesis, of the characteristics and findings of the included studies.

**Transgender**

People who identify with a gender that does not match their sex assigned at birth. (Note: Gender Minorities Aotearoa consider transgender to be the counterpart to cisgender, as its linguistic opposite. Some individuals choose to identify as non-binary or genderfluid as distinct from transgender. In the current paper, these gender minority identities are listed separately from transgender in order to be as inclusive as possible).

**Trans man**

refers to a man who was assigned female at birth, also transgender man

**Trans woman**

refers to a woman assigned male at birth, also transgender woman

**Source:** Gender and sex-related terms were sourced from Gender Minorities Aotearoa [[114](#_ENREF_114)], Stats NZ[[115](#_ENREF_115)]**,** and Te Kāhui Tika Tangata Human Rights Commission [116].

A2.3 Glossary of Te Reo Māori terms

**Aotearoa** New Zealand

**hengahenga** girl

**hine** girl, daughter, term of address to a girl or younger woman

**ia weherua-kore** non-binary gender

**iawhiti** transgender

**kanorau ā-io** neurodiversity (kanorau =diversity, ā-io=of the nerves), see also *Kanorau ā-roro*

**kanorau ā-roro** neurodiversity (kanorau =diversity, ā-roro=of the brain); see also *Kanorau ā-io*

**kaupapa** plan, purpose, agenda, topic, scheme, proposal, policy, subject, programme

**kōhine** girl, maiden, female adolescent

**kōtiro** to be a girl

**māitiiti** youthful man, young man, youth

**mana atua** wellbeing

**rangatahi** young person/people

**tahine** a person who identifies with mixed genders, non-binary, and/or transgender not-otherwise-specified (also ira tāhūrua-kore)

**taihema taketake** biological sex

**taitamāhinetanga** being a young woman

**takatāpui** umbrella term that embraces all Māori with diverse gender identities, sexualities, and sex characteristics including whakawāhine, tangata ira tāne, lesbian, gay, bisexual, trans, intersex, and queer

**takiwātanga** autism (in his/her/their own time and space) [[33](#_ENREF_33)]

**tamaiti** child

**tamāhone** daughter, girl

**tamawahine** daughter, girl

**tama** son, boy, nephew

**tamariki** children

**tamatāna** to be a boy

**tānetanga** maleness, manhood, male sex, masculinity

**tangata ira tāne** ‘trans man’

**tangata ira wahine** ‘trans woman’

**tangata whaitakiwātanga** autistic person (see takiwātanga)

**te reo Māori** the Māori language

**tikanga** customs, protocol, rules, principles

**uha** female (of birds and animals), woman, femaleness, femininity

**uwha** woman, femaleness, femininity

**wāhine** female, women, feminine

**whakawahine** ‘trans woman’; more literally, it translates as being or becoming, in the manner of spirit of a woman

**whānau** extended ‘family’ based on genealogy/whakapapa and includes physical, emotional, and spiritual dimensions

**whanaungatanga** kinship, relationship

**whare tapa whā** framework of Māori health (four-sided house)

**Sources**: Te Reo Hapai [[117](#_ENREF_117)], Te Aka Māori Dictionary [[118](#_ENREF_118)], Gender Minorities Aotearoa [[114](#_ENREF_114)], Public Service Commission [119], Stats NZ [[115](#_ENREF_115)], Te Aka Māori Dictionary [[118](#_ENREF_118)], Te Kāhui Tika Tangata Human Rights Commission [116], Te Reo Hapai [[117](#_ENREF_117)], and Glossary for the 3rd edition of the Guideline [1]

A2.4 Pacific peoples terms

Pacific peoples have their own culturally specific terms to describe cultural and gender identities [119]. These include but are not limited to the following terms:

* Māhū (Tahiti and Hawaii)
* Vaka sa lewa lewa (Fiji)
* Palopa (Papua New Guinea)
* Fa’afafine (American Samoa, Samoa and Tokelau)
* Akava’ine (Cook Islands)
* Fakaleiti or Leiti (Tonga)
* Fakafifine (Niue)

These terms and more make up the acronym MVPFAFF+ as an umbrella term that refers to gender and sexuality expression and roles across Pacific cultures [[120](#_ENREF_120)]. These concepts are more, or just as much, about familial, genealogical, social, and cultural selfhood. This is not an exhaustive list of Pacific peoples’ terms. These cultural and gender identities do not often have an equivalent in English language/terminology.

Papers are presented within each table relating to separate research questions in chronological order by year of publication (oldest first), and within the same year, alphabetically (by first author‘s surname).

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| --- | --- | --- | --- | --- |
| **Ben-Sasson et al., (2019) [**[**16**](#_ENREF_16)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Israel  **Study type**: systematic review & meta-analysis  **Study Quality**: JBI checklist score: 8/11 (medium quality)  **Aims**: to conduct a meta-analysis of sensory symptoms sensory over-responsivity (SOR), under-responsivity (SUR), and sensation seeking characteristics in autistic people compared with typically developing controls and those with other conditions. Tested for gender differences in sensory characteristics.  (only data relevant to autism, and gender, reported here) | **Databases**: Medline, PubMed, CINAHL, Web of Science, PsycINFO, ProQuest Dissertations and Theses  **Search**: Searched from June 2007 –­ June 2018 (updating a 2009 meta-analysis). Transparent detailed selection criteria. Full search terms described. Included citation searching of reference lists of retrieved articles, and contact with authors to identify grey literature and for clarification.  Observed PRISMA reporting.  Selection criteria:   * English language articles * Included a sensory processing questionnaire * Compared ASD with non-ASD group * Measured SOR, SUR or Seeking across several sensory modalities * Provided sensory mean scores and SDs * Excluded animal studies, studies within one family, general population studies, single case research, reporting of sensory scores that mix SOR, SUR, or Seeking * Where samples overlapped, excluded the smaller study | **Method**: double screening and study selection, with discrepancies resolved through discussion among authors.  Critical appraisal not conducted. Coding guide for data extraction used.  Meta-analyses and reported effect sizes (Cohen’s *d)*. Male sex/gender ratio was included as a moderator amongst other variables.  No analysis of publication bias. | **Included**: 55 studies (14 from 2009 analysis and 41 new studies) of 4606 autistic people were included in the meta-analysis, and 5508 typically developing people, 376 with developmental disabilities, and 399 with other clinical conditions.  Gender reported in k=49 studies, with average across studies of 81% male, Range = 37 – 100%.  Where reported (k=48 studies), mean age of the ASD group was 10.9 years; and mean IQ for ASD group was 84.5 (k=26 studies). Studies were mostly Caucasian (k=20 studies, M=73%).  Study designs: questionnaire (quantitative, observational cross-sectional) studies  Study quality: not reported  Publication bias not reported  **Key findings**  Gender had a non-significant moderating effect on sensory symptoms in the meta-analysis models undertaken. | **Author conclusions**: The study was limited in its ability to examine the effects of gender upon sensory symptoms, hence its non-significant moderation across models was not surprising.  This was due to the narrow range and variance of the male ratio leading to a non-normal distribution among the compared studies.  To fully examine this effect more sensory data for autistic females is needed.  **Reviewer’s notes**: Insufficient variance in gender ratios in studies to permit analysis of this variable. |

Appendix 3: Evidence Tables of included studies

Table A3.1: Sex/gender differences in autistic characteristics

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| **Mahendiran et al., (2019) [**[**18**](#_ENREF_18)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Canada  **Study type**: systematic review & meta-analysis  **Study Quality**: JBI checklist score: 6/11 (medium quality)  **Aims**: to conduct a meta-analysis of sex/gender differences in social-communication function in autistic children diagnosed with attention deficit hyperactivity disorder (ADHD) and typically developing individuals  (only data relevant to autism reported here) | **Databases**: Medline, PsycINFO  **Search**: Searched from 2000 ­– September 2017. Transparent detailed selection criteria. Full search terms described. Whether citation searching was performed was not reported.  Observed PRISMA reporting.  Selection criteria:   * Peer reviewed English language journal articles * Included males and females with a diagnosis of ASD (or ADHD) and typically developing (TD) controls, aged 6–18 years * Reporting on measures of social–communication function * Quantitative permitting calculation of standardized mean differences (SMD). | **Method**: single screening, study selection, data extraction and critical appraisal.  Critical appraisal using Quality Assessment Tool for Cohort and Cross-Sectional Studies.  Conducted random effects model meta-analyses and reported SMD. Where heterogeneity was significant, mixed-effects model used to tests for moderator effects of *measure*, and *age* (6-12 years; 12-18 years).  No analysis of publication bias. | **Included**: k=8 studies of autistic people (8 reporting on social functioning and 3 reporting on communication functioning). No synthesis of study characteristics, however determined by current reviewer as reporting on N =576 autistic people (range=23 ­– 173) with mean age ranging from 7.9 – 12.7 and Gender=69% male; and N =538 nonautistic people (range=23 –­ 173) with mean age ranging from 7.9 – 14.0, Gender=57% male.  Measures employed including Social Responsiveness Scale (SRS) total scores  Study designs: quantitative cross-sectional studies  Study quality: appraised but not reported  Publication bias not reported  **Key findings**   * Social communication and interaction skills (k=8 studies) * Social domain (k=8): No significant sex/gender differences were found within ASD (SMD=0.13), or within the TD group (SMD=0.24). No significant sex/gender differences found between ASD and TD groups (SMD = −0.43). Significant heterogeneity was noted in all analyses. *Measure*, and *Age*, were not significant moderators. * Communication domain (k=3): No significant sex/gender differences were found within ASD (SMD=0.25), or within the TD group (SMD=0.02). No significant sex/gender differences were found between ASD and TD groups (SMD = 0.86). Significant heterogeneity was noted in all analyses. *Age* was not a significant moderator. *Measure* was a significant moderator (p=0.02) such that sex/gender differences were only observed between the ASD and TD groups for one measure (ADI-R Nonverbal Communication scale) in one study. Other moderators are likely. | **Author conclusions**: the meta-analysis did not detect sex/gender differences in social and communication function in children with ASD. However, the limited number of studies, small female samples, and heterogeneity of measures/tools used, suggests that conclusions may not be drawn with confidence until larger longitudinal studies that address these issues. Type of measure may have partially accounted for some variability between studies.  **Reviewer’s notes**: Only two databases. Limited by relatively low number of studies, especially for Communication domain outcomes, high heterogeneity, and different measures employed by studies (most were parent-reported). Several of the studies had very few females included (M=22.3), and may be underpowered to detect sex/gender differences. |

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| **Huang et al., (2020) [**[**24**](#_ENREF_24)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |

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| --- | --- | --- | --- | --- |
| **Country**: Australia  **Study type**: systematic scoping review  **Study Quality**: JBI checklist score: 6/11 (medium quality)  **Aims**: to conduct a systematic review to summarise research on autism diagnosis in adulthood.  One theme identified related to gender, and is reported here. | **Databases**: Medline, PsycINFO, EMBASE, CINAHL  **Search**: Searched from 2008 –­ Nov 2018. Transparent detailed selection criteria. Full search terms described. Citation searching performed of included papers.  Observed PRISMA reporting.  Selection criteria:   * English language publications * Included people who underwent or sought first-time diagnosis for ASD in adulthood (M age ≥18 years), their carers, or professionals who diagnose adults * Quantitative and qualitative studies * Published primary studies with n>1 | **Method**: single researcher screening, data extraction, and critical appraisal. Independent double study selection of full text articles (85% agreement).  Critical appraisal analysed using the JBI Critical Appraisal Tools. A mean score of ≥ 1.5 indicates high quality.  Through analysis of phenomena of interest conducted by one author and refined into themes by three authors. | **Included**: k=4 (of 82 studies included in the broader review) explored gender differences relevant to current review. No synthesis of study characteristics, however determined by current reviewer as reporting on N=1627 autistic people (range= 130 – 1244) with ages ranging from 18 – 75 years and Mean % male gender = 67%.  Study designs: Quantitative retrospective or concurrent cross-sectional studies  Study quality: Mean quality appraisal score was high ranging from 1.4–2.0.  Publication bias not reported  **Key findings**:  With respect to the gender research question/theme, the following relevant outcomes were reported.   * Women tended to self-report more autistic characteristics [[98](#_ENREF_98), [99](#_ENREF_99)], but scored similar to men [[100](#_ENREF_100), [101](#_ENREF_101)] on clinician-rated diagnostic tools. | **Author conclusions:** Studies have highlighted a discrepancy between self- reported and clinician-assessed autistic characteristics in adulthood- diagnosed women. Clinicians working with women should consider the interaction between individual capabilities and social demands in making recommendations for diagnosis and support.  **Reviewer’s notes**: As a broad scoping review, gender was not the focus.  Comparison of self-reporting of autistic characteristics with diagnostic scores was made between different studies and populations. The two studies reporting on autistic characteristics were small (both under N=130). |

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| **Melo et al., (2020) [**[**19**](#_ENREF_19)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Canada  **Study type**: systematic review (meta-analysis not reported here as excluded gender)  **Study Quality**: JBI checklist score: 9/11 (high quality)  **Aims**: to conduct a meta-analysis describing prevalence of motor stereotypies, including analyses of factors that influence prevalence including gender, in autistic people  (only data relevant to studies reporting on gender reported here) | **Databases**: Medline, PsycINFO, Scopus  **Search**: Searched from inception –­ July 2018. Transparent detailed selection criteria. Full search terms described. Citation searching performed of included papers.  Observed PRISMA reporting.  Selection criteria:   * Included individuals with a clinical diagnosis of ASD of any age * Reporting on prevalence of stereotypies defined as repetitive body movements and clearly differentiated and described separately from other repetitive behaviours * Quantitative (permitting calculation of SMD) * Included more than 10 participants * Only studies reporting on comparison between males and females are reported here. | **Method**: double screening, study selection, and critical appraisal. Data extraction conducted by single reviewer, reviewed by a second investigator.  Critical appraisal analysed using Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).  Meta-analyses not conducted investigating gender due to insufficient data. | **Included**: 7 studies of autistic people where gender differences were compared. No synthesis of study characteristics, however determined by current reviewer as reporting on n=1285 autistic people (range=13 –­ 325) with mean age ranging from 4.9 – 19.2.; Gender M=66% (61-84%) males.  Study designs: comparative quantitative observational studies (cross-sectional case series or cohort studies)  Study quality: not reported for subset of articles reported here  Publication bias not reported  **Key findings**   * Stereotypies (k=7 studies):   Only one of 7 studies found a gender difference in the prevalence of motor stereotypies. Goldman et al. (2009) found that within the low Non-Verbal IQ group, females had significantly more stereotypies than males (p<0.001, 95% CI = 5.1– 17.1). This effect was not identified in the higher Non-Verbal IQ group. | **Author conclusions**: the influence of gender on motor stereotypies prevalence was not conclusive.  Limitations of the reviewed literature include the use of convenience samples, with small sizes and heterogeneous inclusion criteria, and the predominance of ‘high-functioning’ (less obviously autistic) individuals. There were no population-based studies.  Studies using randomized samples and prospective community longitudinal follow-up of autistic individuals, with defined stereotypies, are recommended.  **Reviewer’s notes**: Three databases. Limited by relatively low number of studies examining gender differences in prevalence. High heterogeneity. Studies may be underpowered to detect sex/gender differences. |

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| **Wood-Downie et al., (2021) [**[**22**](#_ENREF_22)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| Country: UK  **Study type**: systematic review & meta-analysis  **Study Quality**: JBI checklist score: 11/11 (high quality)  **Aims**: to investigate gender differences in narrow construct subdomains and associated behavioural exemplars for social interaction and communication in autistic individuals; whether these mirror those for nonautistic individuals; and whether any gender differences are moderated by age. | **Databases**: PsycINFO, Psych Articles, CINAHL, PubMed  **Search**: Searched from inception –January 2020. Transparent detailed selection criteria. Full search terms described. Citation searching performed of included papers.  Observed PRISMA reporting.  Selection criteria:   * Peer reviewed studies * Included autistic and nonautistic males and females * Reporting on a subdomain (narrow construct) of the DSM5 diagnostic criteria for social interaction and communication * Quantitative cross-sectional studies * Excluded samples of fewer than 6 autistic people, and reporting on outcomes based on diagnostic/screening instruments | **Method**: double screening and selection of sub-samples of abstracts and retrieved articles; data extraction of all included articles; and rating of quality. High (>90%) inter-observer agreement was achieved.  Critical appraisal using Appraisal Tool for Cross-Sectional Studies.  Conducted random effects model meta-analyses and reported SMD. Where there were multiple measures of one construct, means and SDs were pooled. Where heterogeneity was significant, *age* group was investigated a moderating factor (infants/children; children/adolescents; adults).  Publication bias investigated using funnel plots. | **Included**: k=16 studies of autistic people. No synthesis of study characteristics, however determined by current reviewer as reporting on n =1,431 autistic people (range=23-389) with mean age ranging from 0.75 – 35.6 years; and n=1,311 non-autistic people (range=17–381) with mean age ranging from 0.75 – 40 years.  Broad range of measures employed including questionnaires, eye tracking, observational measures or behavioural tasks. Studies measured a range of outcome measures including: peer relationships: (k=6 studies); play behaviours: (k=2); social attention: (k=3); and social reciprocity: (k=1). There was insufficient variability in IQ scores to investigate it as a potential moderating variable.  Study designs: comparative quantitative cross-sectional studies  Study quality: ratings ranged from 12 to 15 out of 20.  Publication bias was significant (p=0.02)  **Key findings**   * Social communication and interaction skills (k=16 studies) * Comparison between autistic individuals * *Autistic females cf autistic males:* small to medium effect (SMD=0.39) of autistic females having *fewer* difficulties than males * Comparison between non-autistic individuals * *Nonautistic females cf nonautistic males:* small to medium effect (SMD=0.35) of nonautistic females having *fewer* difficulties than nonautistic males. Heterogeneity test was significant, and moderating effect of age was significant (p=.007) such that the effects (SMD) increased with higher age groups. * Comparison between autistic and non-autistic individuals * *Nonautistic females cf autistic females*: medium to large effect (SMD=0.72) of nonautistic females having *fewer* difficulties than autistic females. Heterogeneity test was significant, and moderating effect of *age* was significant (p=.001) such that the effects (SMD) increased with higher age groups. Heterogeneity still significant at each age group. * *Nonautistic males cf autistic males*: medium to large effect (SMD=0.77) of nonautistic males having *fewer* difficulties than autistic males. Heterogeneity test was significant. Not significantly moderated by *age*. * *Autistic females cf nonautistic males:* non-significant effect (SMD=0.30; p=0.07) with trend for nonautistic males having *fewer* difficulties than autistic females; heterogeneity test was significant. Not significantly moderated by *age*. | **Author conclusions**: autistic females demonstrated significantly better social interaction and communication skills than autistic males, which mirrored the pattern found for nonautistic individuals.  Both autistic females and males had significantly lower social interaction and communication skills than their nonautistic female and male counterparts.  The difference between nonautistic males with nonautistic females, and autistic females with nonautistic females became more evident with increased age.  Autistic females had lower social interaction and communication skills than nonautistic males but this was not significant.  The review highlights important sex/gender differences in social interaction and communication for autistic individuals, likely not captured by pre-existing diagnostic instruments, which potentially contribute to the under recognition of autism in females, and may need to be reflected in the diagnostic process.  **Reviewer’s notes**: High quality review. Addressed different outcomes to those usually considered in reviews of studies using broad construct measures. Limited by relatively low number of studies reducing ability to investigate moderating factors such as IQ, and age groups with more precision, particularly older individuals. |

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| **Saure et al., (2023) [**[**20**](#_ENREF_20)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: Finland  **Study type**: systematic review & meta-analysis  **Study Quality**: JBI checklist score: 9/11 (high quality)  **Aims**: sex/gender differences in social communication and social interaction, restrictive and repetitive behaviour and interests (RRBI), sensory symptoms, linguistic abilities and motor problems in Autism Spectrum Disorder (ASD) without intellectual disability (ASD only) and ASD with intellectual disability (ASD + ID). | **Databases**: Medline, PsycINFO databases; Google Scholar.  **Search**: Searched from inception –May 2022. Transparent selection criteria. Full search terms described.  Citation searching performed, grey literature searched.  Observed PRISMA reporting.  Selection criteria:   * English language, peer-reviewed * Compared autistic females with autistic males * Reported gender differences on at least one of the following: communication and social interaction; RRBI, or sensory symptoms; linguistic abilities; motor abilities; cognitive skills; emotion recognition behavioural characteristics; comorbidity (only characteristics relating to core characteristics are reported here). * Statistical analysis of means and Standard Deviations (SD) * Intelligence Quotient (IQ) or Developmental Quotient (DQ) reported. | **Method**: independent double study screening and selection of retrieved articles.  Critical appraisal tool assessing the Risk of bias was the Newcastle–Ottawa Scale.  Random effects meta-analyses undertaken.  Effect sizes presented as standardised mean difference (SMD). | **Included**: k=79 studies (n =14,758 autistic people; 28% with ID). N=10,550 autistics without ID, mean age of 15 years; gender=70% male  N=4208 autistics with ID, M age = 9 years; gender=70% male.  Study designs: comparative, quantitative observational studies  Study quality: Most studies were rated 7–8 out of 10 and no fewer than 5.  Publication bias: no evidence in funnel plots.  **Key findings**   * Social communication and social interaction: (k=54 studies) uncertain effect (SMD=-0.17, k=39 studies) of autistic females without ID having *fewer* difficulties than autistic males without ID; whereas small effect for autistic females with ID having *more* difficulties than autistic males with ID (SMD=0.20, k=15 studies). There was a Group (with and without ID) effect (p<0.001) in opposite directions in gender differences. * Restrictive and repetitive behaviour and interests (RRBI): (k=49 studies): small effect (SMD=-0.23, k=40) of autistic females without ID having *fewer* RRBI than autistic males without ID; whereas uncertain effect for autistic females with ID having *more* difficulties than autistic males with ID (SMD=-0.11, k=9). There was a trend for a group (ID status) effect of p=0.06. * Sensory processing: (k=18 studies): small to medium effect (SMD=0.37, k=18) of autistic females without ID having *more* sensory challenges than autistic males without ID; and also, a small effect for autistic females with ID having *fewer* challenges than autistic males with ID (SMD=-0.21, k=4). Effects were in opposite directions with a group effect (ID status) of p=0.002. | Author conclusions:  Results clearly suggest that the female phenotype of ASD is moderated by ID.  The female phenotype differs from the male phenotype in ASD among both individuals with and without ID, but in several studied domains, sex/gender differences have the opposite direction. Among autistic individuals with ID, girls/women seem to be more severely affected than boys/men.  Among autistics without ID, females may be less affected than males. In the context of social communication and social interaction, the effect size for gender differences in autistics without ID was below 0.2, suggesting that the sex/gender differences are negligible.  Such phenotypic gender-based differences could be a potential cause of under-recognition of girls/women with ASD, or alternatively, could reflect underdiagnosing of girls/women with ASD.  Heterogeneity is large and there are still only a small number of studies in some categories, sometimes with studies reporting opposite findings. One factor potentially contributing to the heterogeneity is the possibility of camouflaging of autistic characteristics.  **Reviewer’s notes**: Recent review of quantitative studies, broad cover of autistic characteristics. Considers populations with and without ID separately. |

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| **Key**: ADHD=Attention Deficit Hyperactivity Disorder; ADI-R=Autism Diagnostic Interview-Revised; ASD=Autism Spectrum Disorder; CI=confidence interval; CINAHL=Cumulative Index to Nursing and Allied Health Literature; d=Cohen’s d, an indicator of effect size; DSM5=Diagnostic and Statistical Manual of Mental Disorders – 5th edition; ID=intellectual disability; IQ= intelligence quotient; JBI=Joanna Briggs Institute; k=number of studies; M=mean; MEDLINE=Medical Literature Analysis and Retrieval System Online; n=number of people; PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PsycINFO=Psychological Information Database; RRBI=restrictive and repetitive behaviour and interests; SD=standard deviations; SMD=standardised mean difference; SOR=sensory over-responsivity; SRS=Social Responsiveness Scale; STROBE=Strengthening the Reporting of Observational Studies in Epidemiology; SUR=sensory under-responsivity; TD=typically developing; UK=United Kingdom |

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| **Loubersac et al., (2021) [**[**17**](#_ENREF_17)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: France  **Study type**: systematic review  **Study Quality**: JBI checklist score: 8/11 (medium quality)  **Aims**: to identify average age at which the diagnosis of ASD is confirmed, and associated environmental factors (including gender)  (only data relevant to studies reporting on gender reported here) | **Databases**: Pubmed, Web of Science, PsycINFO, Cochrane Library  **Search**: Searched from inception – ­ Dec 2019. Transparent detailed selection criteria. Full search terms described. Whether citation searching was performed was not reported.  Observed PRISMA reporting.  Selection criteria:   * English or French language original publications * included children with a clinical diagnosis of ASD of any age * Reporting on mean and median age at diagnosis * analysis of the link between the age at diagnosis and one or more explanatory factors * Only studies considering gender differences in age of diagnosis are reported here. | **Method**: single screening and study selection, with a random subset of 20% double. Data extraction conducted by single reviewer, reviewed by a second investigator.  Critical appraisal assessing risk of bias conducted by three investigators using Newcastle Ottawa Scale (NOS). | **Included**: k=14 studies of autistic people where gender differences were compared. No synthesis of study characteristics, however determined by current reviewer as reporting on N=75,121 autistic people (range=48 ­ 28,722) with mean age ranging from 3 – 9 years. Gender not reported.  Study designs: comparative quantitative observational cohort studies  Study quality: not reported for subset of articles reported here  Publication bias not reported  **Key findings**  None of the 14 studies that investigated the association between gender and age of diagnosis found a significant association. | **Author conclusions**: Gender does not appear to be significantly associated with the age of diagnosis. However, this result must be balanced by the low representation of girls in the study samples, with a sex/gender ratio of 2:1 to 5:1 (males to females) or even a very low representation in 3 studies in which the sex/gender ratio was between 6:1 and 12:1.  Concluded that there is a low level of evidence concerning associations between the age at diagnosis and sex. Further studies using large and well-characterized data sets are needed to simultaneously explore clinical and socio-environmental factors involved in early diagnosis.  **Reviewer’s notes**: Study considered sex/gender amongst a range of possible factors. 50 studies included in the review, only 14 explicitly investigated sex/gender as a possible factor. |

Table A3.2: Sex/gender differences in age of autism diagnosis

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| **Van ‘t Hof et al., (2021) [**[**21**](#_ENREF_21)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| **Country**: The Netherlands  **Study type**: systematic review and meta-analysis  **Study Quality**: JBI checklist score: 6/11 (medium quality)  **Aims**: to identify average age at which the diagnosis of ASD is confirmed.  (only data relevant to studies reporting on sex/gender differences are reported here) | **Databases**: Pubmed, and used its ‘similar articles’ function.  **Search**: Searched from 2012 ­– June 2019. Very limited broad search. Full search terms described. Whether citation searching was performed was not reported.  Observed PRISMA reporting.  Selection criteria:   * English language publications * included (or permitted determination of) an estimate of age at diagnosis for ASD for a sample * Reporting on mean and/or median age at diagnosis | **Method**: double screening, study selection, and data extraction.  Critical appraisal assessing risk of bias conducted using the JBI tool.  Conducted random effects model meta-analyses using the model variance estimator due to large heterogeneity.  Unable to assess publication bias through funnel plots as there was no effect size. | **Included**: k=56 studies included N=120,540 autistic people with mean age at diagnosis ranging from 30.9 to 574.4 months (reported for k= 46 studies). Sex/gender (or sex/gender range) was M = 79.1% male ( reported for k= 51 studies).  Study designs: observational quantitative cohort studies  Study quality: risk of bias ranging from lowest (0) to highest (9) averaged at 3.6  Publication bias not able to be assessed  **Key findings**  Gender differences were compared for 19 studies.  Three studies reported finding a later age at diagnosis for girls than boys in general.  In two studies, there were mixed effects for different subgroups. One of these reported a later age at diagnosis for girls with Asperger’s syndrome, but not with PDD-NOS or ASD. The other reported a later age at diagnosis in girls in the complex-phrase speech subgroup, but not in non-verbal or minimally verbal children.  No effect of sex/gender on age at diagnosis was found in 14 studies, 13 involving children/adolescents alone, and one study including autistic people of all ages. | **Author conclusions**: It is challenging to draw conclusions based on the results we found as most are inconsistent and/or have not been explored thoroughly. Extensive studies – evaluating a wide variety of factors and using a study design that enables adjusting for covariates – are needed to gain insight into which factors affect age at ASD diagnosis.  **Reviewer’s notes**: Only one database used. Evaluating factors affecting the age at ASD diagnosis was not a primary aim of this review and meta-analysis.  Only 22 studies explicitly investigated sex/gender as a possible factor, and sex/gender was not included in the meta-analysis as a moderating variable. No synthesis of study characteristics for sex/gender studies. |

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| **Key**: ASD=Autism Spectrum Disorder; JBI=Joanna Briggs Institute; k=number of studies; NOS=Newcastle Ottawa Scale; PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PsycINFO=Psychological Information Database |

Table A3.3: Sex/gender differences in autistic masking

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| **Cook et al., (2021) [**[**23**](#_ENREF_23)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| Country: UK  **Study type**: systematic review  **Study Quality**: JBI checklist score: 9/11 (high quality)  **Aims**: systematically appraise and synthesise the current evidence base pertaining to autistic camouflaging (or masking or compensation) in children and adults with autism diagnoses or high levels of autistic characteristics  (only data relevant to sex/gender differences are reported here) | **Databases**: Medline, Embase, Web of Science, PsycINFO, Scopus. Additional grey literature searching of ProQuest Dissertations, Theses Global, Google Scholar, and PsyArXiv  **Search**: Searched from inception ­ Oct 2020, updated May 2021. Transparent detailed selection criteria. Full search terms described. Citation searching was performed, and experts consulted for *in press* articles.  Observed PRISMA reporting.  Selection criteria:   * Peer reviewed English language articles published or accepted in academic Journals * autistic children and adults with clinical diagnoses of autism, or high levels of autistic characteristics * Reporting quantitative data measuring camouflaging strategies or behaviour | Method: screening conducted by a single researcher, with study selection independently conducted by two researchers, with discrepancies resolved through consensus by four researchers.  Data extraction of 25% of studies was conducted independently by four reviewers, cross-checked for a separate 25% with discrepancies  Critical appraisal was assessed independently by two researcher pairs using the Mixed Methods Appraisal Tool (MMAT), with discrepancies resolved through consensus.  Camouflaging was measured either as an internal-external discrepancy (showing higher autistic characteristics but with less autistic behaviour observed) or self-report (self-perceived camouflaging efforts). | Included: k=29 studies.  *Studies of children and adolescents* (k=11) reported on N = 1077 autistic people (range=33 -­– 236), aged M = 11.9 years (range = 5 – 18). Where reported, most were male or identified as boys (63%), most were white (76%), and were of average IQ. Nine of these studies reported on sex/gender differences.  *Studies of* *adults* (k=18) reported on N=2254 autistic people (range=17-­ 354). Where reported, most were female or identified as women (60%), most were white (86%), typically diagnosed in adulthood (M = 33 years), and were of average/above average IQ. Nine of these studies reported on sex/gender differences.  Study designs: quantitative study designs (k=23), mixed designs (k=3), qualitative designs which included a quantitative measure (k=3)  Study quality: described qualitatively. Overall quality was described as sound. However most (k=23) failing to obtain a representative sample of autistic participants, and/or did not provide drop-out rates. Ten studies failed to account for between group differences in design or analyses.  Publication bias: not investigated  **Key findings**  Studies of children/adolescents: k=7/9 studies suggested that girls camouflaged more than boys, 5 of which measured camouflaging using the internal-external discrepancy approach.  Studies of adults: k=5/9 studies suggested that females camouflaged more than males, 2 of which measured camouflaging using the internal-external discrepancy approach. The three exploratory, mainly qualitative studies found no sex/gender difference. One study reported non-binary gendered people camouflaged more than those identifying as men. One study reported autistic females reported camouflaging more often, across more situations, and for more of the time.  Mental health outcomes: For adults, 8/10 studies supported a relationship between increased self-reported camouflaging and poorer mental health. Three studies yielded some preliminary evidence supporting an association between camouflaging and poorer mental health in children and adolescents. | **Author conclusions**: Despite significant variation in findings, preliminary findings suggest sex and gender differences exist in camouflaging.  However, the research base was limited regarding participant characterisation and representativeness, which suggests that conclusions cannot be applied to the autistic community as a whole.  **Reviewer’s notes**: Comprehensive search strategy. Included people with high levels of autistic characteristics, not just diagnosis, however as the camouflaging may reduce likelihood of seeking or obtaining a diagnosis this seems appropriate. Study considered sex/gender amongst a range of possible factors. No synthesis of study characteristics for sex/gender studies. |

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| **Libsack et al., (2021) [**[**25**](#_ENREF_25)**]** | | | | |
| Country, study type, aim | Search strategy | Appraisal methods | Results | Conclusions |
| Country: USA  **Study type**: systematic review  **Study Quality**: JBI checklist score: 8/11 (medium quality)  **Aims**: systematically identify and synthesize the literature on passing as non-autistic (PAN).  (only data relevant to sex/gender differences are reported here) | **Databases**: Pubmed, PsycINFO.  **Search**: Searched from inception -­ May 2020. Transparent detailed selection criteria. Full search terms described. Citation searching was performed, and additional citations identified through considering articles which cited included studies using Google scholar.  Observed PRISMA reporting.  Selection criteria:   * Peer reviewed English language publications in Journals or PhD dissertations * Empirically investigates behaviour involved in PAN in human autistic subjects (formally diagnosed or self-identified). Some studies also included a third category of people who identified as having significant difficulties in social situations and/or scored highly on measures of autistic characteristics. These are reported separately from autistic people. | **Method**: double researcher screening (88% agreement), and 4 researchers conducted selection.  Critical appraisal was not conducted but data was extracted independently by four researchers using a coding manual, with discrepancies resolved through consensus.  PAN was coded as masking, camouflage, compensation, passing, assimilation, adaptation, and other (based on unique terms used by participants). | **Included**: k=46 studies reported on N = 5980 people (M=130; range=1 ­ 832), 63% (N=3771) of whom are categorised as autistic.  Two studies did not report sex/gender. Of 44 studies that did, there were 49% females, 46% males, 3% neither male or female, and 2% unreported. 8 studies included only one sex/gender, 7 of which included females only.  Age: M = 24 years (range 2 – 79).  Ethnicity was only reported in 24% of studies (84% participants being white).  Nearly all studies formally or informally excluded participants with an intellectual disability.  Acknowledged that some sample overlap may have occurred.  Study designs: mix of qualitative, quantitative, and mixed-method studies.  Study quality: not investigated.  Publication bias: not investigated  **Key findings**  Participants were disproportionately female. Multiple studies in the current review also included female-only samples.  k=19 studies compared PAN across sexes/genders.  k=17 studies (89.47%) reported findings supporting group differences between sexes/genders in behaviours thought to be associated with PAN.  Patterns of effect size and direction of the association were not broadly interpretable due to inconsistencies arising from the wide variation in participant characteristics, sample size, study design, and construct measurement  Among 2 studies that used the same self-report methodology (CAT-Q) found higher rates of PAN among adult females compared to adult males and one study reported no sex/gender differences in rates of PAN among autistic adolescents.  Of 7 studies that directly examined rates of PAN across sexes/genders and utilized discrepancy metrics to measure PAN, 5 studies (k=4 adults only) reported greater rates of PAN among autistic females compared to autistic males. However, this should be interpreted with caution, as use of specific measurement tools was not consistent across 5 studies, and 3 studies included partially overlapping samples. | **Author conclusions**: research participants are disproportionately white females over the age of 18 with average to above average intellectual ability.  There is some preliminary evidence that rates of PAN may be higher for autistic females than autistic males. However, inconsistency of measurement approaches and prevalence of overlapping samples limit firm conclusions at this time  Evidence of an association between PAN and sex/gender may be premature due to wide variations in sample characteristics and construct measurement across studies.  There is inconsistency in assessment method and identified construct, as well as exclusion of specific groups of autistic people.  **Reviewer’s notes**: Very inclusive criteria, including case reports and theses.  Study did not aim to measure whether females were more like to exhibit PAN behaviour than males. Rather it aimed to document reporting practices of study samples. Studies were not formally critically appraised which reduced the quality score. |

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| **Key**: ASD=Autism Spectrum Disorder; CAT-Q=Camouflaging Autistic Traits Questionnaire; EMBASE=Excepta Medica Database; ID=intellectual disability; IQ=intelligence quotient; JBI=Joanna Briggs Institute; k=number of studies; M=mean; MEDLINE=Medical Literature Analysis and Retrieval System Online; MMAT=Mixed Methods Appraisal Tool; n=number of people; PAN=passing as non-autistic; PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PsycINFO=Psychological Information Database; UK=United Kingdom, USA=United States of America |

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1. <https://www.education.govt.nz/our-work/overall-strategies-and-policies/ka-hikitia-ka-hapaitia/> [↑](#footnote-ref-1)
2. Gender Minorities Aotearoa consider transgender to be the counterpart to cisgender, as its linguistic opposite, encompassing all gender identities that do not match their sex assigned at birth. Some individuals choose to identify as non-binary or genderfluid as distinct from transgender. In the current paper, these gender minority identities are listed separately from transgender in order to be as inclusive as possible. [↑](#footnote-ref-2)
3. This Guideline was excluded as there were no eligible unique articles included in their evidence tables. Note that this Guideline is currently being revised. [↑](#footnote-ref-3)
4. These were the response categories reported. [↑](#footnote-ref-4)
5. See https://www.health.govt.nz/system/files/documents/publications/achieving-equity-in-health-outcomes-summary-of-a-discovery-process-30jul2019.pdf [↑](#footnote-ref-5)
6. For example, see: <https://inclusive.tki.org.nz/guides/planning-for-diversity/> [↑](#footnote-ref-6)