Guideline Supplementary Paper

New Zealand Autism Spectrum Disorder Guideline supplementary paper on implications of DSM-5 for the diagnosis of ASD



With the support of the New Zealand Autism Spectrum Disorder

Living Guideline Group

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**Funding and independence**

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The work was researched and written by INSIGHT Research Ltd employees or contractors and the recommendations were the formulation or revised by members of the Living Guideline Group. Appraisal of the evidence, recommendations and reporting are independent of the Ministries of Health and Education.

**Statement of intent**

INSIGHT Research produces evidence-based best practice guidelines, health technology assessments and literature reviews to help health care practitioners, policy-makers and consumers make decisions about health care in specific clinical circumstances. The evidence is developed from systematic reviews of international literature and placed within the New Zealand context.

Guidelines, including supplementary papers, are not intended to replace the health practitioner’s judgment in each individual case.

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This report is dedicated to the memory of our colleague and friend, the late Joanna Curzon, who was instrumental in the development of the New Zealand Autism Spectrum Disorder Guideline and in establishing and supporting the living guideline process.

Haere i muri i te tuarā o Te Whāpuku –

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

Executive Summary

Preamble

The New Zealand Autism Spectrum Disorder Guideline [[1](#_ENREF_1)] was published in April 2008. To ensure that the guideline remains current in the light of emerging research, a living guideline process was established in 2009. The living guideline process aims to regularly update the Guideline to reflect new evidence and changing user needs.

A multidisciplinary team of advisors known as the Living Guideline Group (LGG) prioritise areas for update and revise guideline recommendations after careful consideration of a critical review of the evidence. For the current update topic, a review of evidence, undertaken by INSIGHT Research, and the revised guideline recommendations are presented here as a supplementary report to the original ASD Guideline [[1](#_ENREF_1)]. This document needs to be read in the context of the guideline’s recommendations.

The review and the entire living guideline process were funded by New Zealand’s Ministry of Health, and sponsored by the Ministry of Education.

Scope

The latest area prioritised for update by the LGG relates to changes in the diagnostic criteria for Autism Spectrum Disorder (ASD) published in the latest version of the Diagnostic and Statistical Manual of Mental Disorders - Version 5, the DSM-5 [[2](#_ENREF_2)].

A critical review of this topic describes the changes to DSM-5’s diagnostic criteria relating to ASD and their rationale, critically summarises relevant empirical research, and outlines key clinical, social and research issues potentially impacted by the application of these changes. The primary goal has not been to judge whether or not the diagnostic changes are necessarily a good idea, but to focus on whether and how the New Zealand ASD Guideline needs to change to reflect them.

Areas beyond the scope of this report include formal critique or commentary on:

* revision of the other major classification system for disorders, the International Classification of Diseases (ICD-11)
* assessment tools relating to the diagnosis of ASD and associated measures
* public policy in New Zealand around eligibility for and access to ASD services in light of the DSM-5.

Summary of DSM-5 changes to the diagnosis of ASD

Differences to the diagnostic criteria relating to autism spectrum between DSM-IV-TR and DSM-5 are summarised in **Table 1.1**.

Key changes in the diagnostic classification of ASD in the DSM-5 include:

* The previous version of the manual distinguished conditions as separate subtypes including autistic disorder, Asperger’s disorder (Asperger syndrome), and pervasive developmental disorder not otherwise specified (PDD-NOS). However the new version (DSM-5) subsumes these conditions under a single diagnosis of autism spectrum disorder (ASD) with the subtypes no longer specified.
* Criteria previously organised into three symptom domains are now presented under two domains:

(1) social communication and social interaction

1. restricted, repetitive patterns of behaviour, interests, or activities.

* The number of symptoms within the domains has been streamlined from 12 to 7. For a diagnosis of ASD, all 3 criteria on the social-communication domain must be present and 2 of 4 criteria in the restricted interests domain must be met.
* Notably, behaviours do not have to be currently present, they may be present only in history (eg, observed in childhood).
* Sensory behaviours (hypo- and hyper-reactivity to sensory input or unusual interest in sensory aspects of the environment), absent from DSM-IV criteria for ASD, are now included under the restricted, repetitive patterns of behaviours domain.
* Dimensional elements have been introduced to reflect how much a condition affects an individual (its “severity” level) in terms of broadly indicating how much support a person needs and in what areas of function.
* Clinical “specifiers” have been introduced to help describe accompanying difficulties and need for supports, including their intellectual ability, language impairment, and co-occuring medical conditions. Delays in language will affect an individual's clinical presentation but is not a defining diagnostic autism spectrum criterion.
* The requirement that symptoms be evident before the age of 36 months has been removed and replaced with a more open definition of “present in the early developmental period”.
* A new ASD criterion requires that the constellation of symptoms together must “cause clinically significant impairment in social, occupational, or other important areas of current functioning”.
* Another new ASD criterion requires that these disturbances are not explained by alternative diagnoses of intellectual disability or global developmental delay.
* Diagnosis of comorbidities including attention-deficit/hyperactivity disorder (ADHD), stereotyped movement disorder and psychiatric conditions such as anxiety states and schizophrenia are now permitted with ASD.
* A new condition called “social communication (pragmatic) disorder” (SCD) has been included. This applies where someone exhibits the social communication and interaction aspects of an autism spectrum disorder diagnosis, but does not show restricted, repetitive patterns of behaviour, interests or activities.
* The DSM-5 advises that people who already have a definitive diagnosis of Autistic disorder, Asperger’s disorder (Asperger syndrome) or PDD-NOS will (continue to) retain a diagnosis of autism spectrum disorder.

Review of evidence

Following a comprehensive database search and reference checking of research published since 2004, 123 articles were retrieved as full text, and 93 relevant to the review scope were critically reviewed. The dedicated DSM-5 website and those of prominent autism organisations were searched for position statements and featured commentaries to provide further background to the diagnostic changes.

Preliminary indications of clinical utility are positive. In DSM-5 field trials [[4](#_ENREF_4)], inter-rater reliability appears to be good, although the sample for ASD diagnosis was small and requires verifying in broader populations. The revised diagnostic criteria appear to be acceptable and feasible in trials in routine practice settings, at least for motivated participants following significant online training [5].

Fourteen studies were identified which investigated the diagnostic yield of ASD when applying the new DSM-5 criteria compared with DSM-IV. Studies provided widely ranging estimates of test accuracy generally consistent with improved specificity for DSM-5 (fewer people without ASD being mistakenly diagnosed with the condition) but somewhat reduced sensitivity (the ability to correctly diagnose people with the condition). Interpretation is hampered by methodological differences and limitations. A study of over 5000 children and young people published in October 2012 found that a high majority (91%) of people diagnosed with an ASD under DSM-IV-TR criteria (identified retrospectively) would retain a diagnosis of ASD under DSM-5 criteria [[6](#_ENREF_6)]. Specificity was not high but was improved over DSM-IV-TR.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **DSM-IV-TR: Autistic disorder** | | **DSM-5: Autism spectrum disorder** |
| No. criteria=12, minimum criteria=3, domains=3 | | No. criteria=7, minimum criteria=5, domains=3 | |

Table 1.1. Summary of differences between DSM-IV-TR and DSM-5 Criteria[[1]](#footnote-1)

**Social Interaction Domain (minimum required: ≥2 of 4) Social Interaction and Social Communication (minimum required: all 3)**

|  |  |
| --- | --- |
| **1A.** Marked impairments in the use of multiple nonverbal behaviors to regulate social interaction | **A2.** deficits in nonverbal communicative behaviors used for social interaction |
| **1B.** Failure to develop peer relationships appropriate to developmental level | **A3.** deficits in developing and maintaining relationships appropriate to developmental level |
| **1C.** A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people | *(Subsumed into* ***A1****)* |
| **1D.** Lack of social or emotional reciprocity | **A1.** deficits in social emotional reciprocity |

**Communication Domain (minimum required: ≥2 of 4) Social Interaction and Social Communication (minimum required: all 3)**

|  |  |
| --- | --- |
| **2A.** Delay in, or total lack of, the ability to use spoken language | *(Criterion removed)* |
| **2B.** Marked impairment in the ability to initiate or sustain a conversation with others | *(Subsumed into* ***A1****)* |
| **2C.** Stereotyped or repetitive use of language or idiosyncratic language | *(Subsumed into* ***B1****)* |
| **2D.** Lack of varied, spontaneous make-believe or social imitative play appropriate to developmental level | *(Subsumed into* ***A3****)* |

**Restricted Interests & Repetitive Behaviors Domain (minimum: ≥1 of 4) Restricted Interests and Repetitive Behaviors Domain (minimum required: ≥2 of 4)**

|  |  |
| --- | --- |
| **3A.** Encompassing preoccupation with ≥1 stereotyped and restricted pattern of interest abnormal in intensity or focus | **B3.** highly restricted fixated interests that are abnormal in intensity or focus |
| **3B.** Apparently inflexible adherence to specific routines or rituals | **B2.** excessive adherence to routines, ritualised patterns of verbal or nonverbal behavior, or excessive resistance to change |
| **3C.** Stereotyped and repetitive motor mannerisms | **B1.** stereotyped or repetitive speech, motor movements, or use of objects |
| **3D.** A persistent preoccupation with parts of objects | *(Criterion removed or possibly subsumed into* ***B3****)* |
|  | **B4.** Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment |

**Additional Criteria for DSM5: Autism spectrum disorder**

|  |
| --- |
| **C.** symptoms must be present in early childhood (but may not fully manifest until social demands exceed limited capacities) |
| **D.** symptoms together limit and impair everyday functioning |
| **E.** Intellectual disability or global developmental delay should be considered as preferential diagnoses |

Until high quality prospective trials are published, assessment tools are finalised and validated, and clinicians begin to apply the new criteria prospectively, many of the questions about clinical use and impact on prevalence of ASD remain uncertain. This is particularly the case for the new disorder of Social (Pragmatic) Communication Disorder. As DSM-5 is intended to be a living document, revisions are anticipated where justified by new research.

DSM criteria provide the foundation for the development of diagnostic tools, which require revision, development and validation in light of the DSM-5. However it is important to recognise that, ultimately, clinical judgement requires a global assessment of whether someone has symptoms which cause impairment to their everyday functioning.

Conclusions

Autism has been considered a spectrum condition for many years, as recognised in the New Zealand ASD Guideline [[1](#_ENREF_1)]. The rationale behind the revisions of the clinical manual is evidence-based, supported by a rigorous, transparent and consultative development process by an international team and extending over many years.

The Living Guideline Group echoes the UK’s National Autistic Society (NAS) [[7](#_ENREF_7)] in finding the DSM-5 revised diagnostic criteria helpful, being clearer and simpler than the previous DSM-IV criteria, and in welcoming the development of dimensional measures of severity, the inclusion of sensory behaviours, and the emphasis on identifying the full range of difficulties that an individual may experience as well as other relevant factors. The LGG also observe that whilst Asperger syndrome may no longer be a distinct diagnostic entity diagnosed under the DSM-5, the concept retains clinical utility in terms of family understanding, self identity, and as a tool for guiding educational and behavioural interventions and informing services and supports.

The Living Guideline Group recognises that people who identify closely with the term Asperger syndrome may continue to use it in everyday language. Regardless of the changes to the classification of ASD in what is fundamentally a diagnosticians’ clinical manual, individuals may choose to refer to themselves using their own terms of belonging to a culture that transcends psychiatric diagnosis.

How to read the ASD guideline in view of DSM-5

The NZ ASD Guideline (2008) [1] was prescient in recognising the movement toward considering autism as a spectrum condition and in the Guideline’s title and frequently throughout the text and recommendations, the umbrella term of Autism Spectrum Disorder has been used. Nevertheless, when the original guideline was written the DSM-IV-TR manual was current and the terms Asperger syndrome and PDD-NOS were used in research. The Living Guideline Group advise that, in view of the DSM-5, where these terms are used in the Guideline they should be read as refering to ASD.

Summary of revised and new recommendations

Given the DSM-5’s changes to criteria for diagnosis of ASD outlined above, some revisions to recommmendations are necessary.

Deleted good practice point relevant to diagnostic classification of people with ASD

|  |  |  |
| --- | --- | --- |
| Original Reference | Deleted good practice point | Grade |
| 1.3.5 | Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary. | **✔** |

Revised recommendations relevant to diagnostic classification of people with ASD

|  |  |  |
| --- | --- | --- |
| Original Reference | Revised recommendations | Grade |
| 1.2.5 | Standardised ASD assessment interviews and schedules should be used. | **B** |
| 1.2.7 | The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed. | **B** |
| 6.2 | Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established. | **C** |
| 6.3 | Norms should be developed for ASD assessment tools specifically for the New Zealand population. | **C** |

New good practice point relevant to diagnostic classification of people with ASD

|  |  |  |
| --- | --- | --- |
| New Reference | New Good Practice Point | Grade |
| 1.2.14 | Assessment should consider the influence of diversity such as ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographical location. | **✔** |
| 1.2.15 | Decisions about whether to undertake an assessment of an individual should elicit and consider whether that person requires, would value, and would benefit from a diagnosis of ASD. | **✔** |

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About the evidence review

Purpose

The New Zealand Autism Spectrum Disorder Guideline (the ASD Guideline) [[1](#_ENREF_1)] was published in April 2008. As part of their commitment to the implementation of the guideline, New Zealand’s Ministry of Health and Ministry of Education agreed to establish a Living Guideline process in 2009. This process was initially developed by the New Zealand Guidelines Group (NZGG) and since 2012, managed by INSIGHT Research. The living guideline process is where a guideline is regularly updated and refined to reflect new evidence and changing user needs.

Updates within the living guideline process are required when the recommendations in the guideline are no longer considered valid in view of research evidence that has emerged since the guideline’s literature searches were conducted. A multidisciplinary team of advisors form the Living Guideline Group (LGG) which is responsible for identification of areas for update, consideration of new evidence and reporting on any implications for guideline recommendations. Current members of the LGG are listed in **Appendix A1.1**.

This supplementary report describes a critical review of research and commentary relating to changes proposed to the diagnostic classification of Autism Spectrum Disorder (ASD) published in the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders - Version 5 (DSM-5) [[2](#_ENREF_2)], which was released in May 2013. The review was undertaken by INSIGHT Research to support the work of the ASD Guideline’s Living Guideline Group (LGG).

Also reported are revised and new recommendations developed by the Living Guideline Group following consideration of the reviewed evidence.

This report is the fifth in a series of supplementary reports [[8-11](#_ENREF_8)] produced to update the ASD Guideline [[1](#_ENREF_1)].

This review and the entire living guideline process was funded by New Zealand’s Ministry of Health, and sponsored by the Ministry of Education.

Scope of the evidence review

The Living Guideline Group have identified changes in the diagnostic criteria for Autism Spectrum Disorder (ASD) in the latest version of the Diagnostic and Statistical Manual of Mental Disorders - Version 5 (DSM-5) [[2](#_ENREF_2)], published in May 2013, as an area which could require revised or additional recommendations in the ASD guideline [[1](#_ENREF_1)]. This document needs to be read in context of recommendations in the ASD Guideline [[1](#_ENREF_1)].

This review aims to describe the changes to DSM-5’s diagnostic criteria relating to ASD and their rationale, critically summarise relevant empirical research, and outline key clinical, social and research issues potentially impacted by the application of these changes. The primary goal is not to judge whether or not the diagnostic changes are necessarily a good idea, but instead to focus on whether and how the New Zealand ASD Guideline needs to change to reflect them.

The other major classification system for disorders, the World Health Organisation’s (WHO) International Classification of Diseases (ICD-11), is being revised with publication expected in 2015. Detailed analysis of revisions related to this system is beyond the scope of this report.

Also beyond scope is any formal critique of assessment tools relating to diagnosis of ASD, including the DSM-5’s “emerging measures”.

It is recognised that DSM-5’s changes to diagnosis of ASD may contribute to the development of government policy regarding eligibility for and access to ASD services. Whilst discussions around potential implications for such services internationally are outlined, explicit comment on public policy in New Zealand is beyond the scope of the work of the Living Guideline Group and this report.

Definitions

To ensure consistency with the NZ ASD Guideline, in this review the term Asperger syndrome (AS) is used to refer to both Asperger’s Disorder and Asperger syndrome. The acronym ASD (Autism Spectrum Disorder) is used to refer to a condition on the autism spectrum to distinguish it from AS and also to conform with the original guideline’s terminology.

The term autism spectrum disorder is used to refer to those pervasive developmental disorders identified in DSM-5’s predecessor, DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders version 4, text revision), which are generally understood to refer to ASD’s; namely Autistic Disorder, Childhood Disintegrative Disorder (CDD), Asperger's Disorder and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS).

Target audience

This evidence review and guidance update is intended primarily for the providers of professional services for New Zealanders with ASD. It is also expected that the recommendations will be accessed by people with ASD and their families.

Treaty of Waitangi

INSIGHT Research acknowledges the importance of the Treaty of Waitangi to New Zealand, and considers the Treaty principles of partnership, participation and protection as central to improving Māori health.

INSIGHT Research’s commitment to improving Māori health outcomes means we attempt to identify points in the guideline or evidence review process where Māori health must be considered and addressed. In addition, it is expected that Māori health is considered at all points in the guideline or evidence review in a less explicit manner.

Recommendation development process

The research question(s) were identified and prioritised by the Living Guideline Group and were used to inform the search of the published evidence. A one day, face-to-face meeting of the Living Guideline Group was held on 26 November 2013, where reviewed evidence and its impact on existing recommendations in the NZ ASD Guideline [[1](#_ENREF_1)], or the need for new recommendations, was considered.

INSIGHT Research follows specific structured processes for evidence synthesis. Full methodological details are provided in **Appendix 1**. This appendix also includes details of the Living Guideline Group membership and lists the organisations that provided feedback during the consultation process. **Appendix 2** presents a glossary of key epidemiological and statistical terms, abbreviations and acronyms. **Appendices 3** and **4** present criteria for diagnoses relevant to Autism Spectrum Disorder in the DSM-IV-TR and DSM-5, respectively. **Appendix 5** summarises DSM-5’s online emerging assessment measures**.**

1 Introduction

1.1 Background

Diagnostic classification systems

Autism cannot be diagnosed by medical tests of biological markers but is determined clinically through the observation of behavioural features meeting explicit diagnostic criteria. These are detailed in formal classification systems including the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) and the World Health Organisation’s (WHO) International Classification of Diseases and Related Health Problems (ICD).

The DSM sets out the symptoms and definitions of “mental disorders” that are recognised by the psychiatric profession, and serves as a reference handbook for clinicians in the United States and throughout the world. It provides “the standard language” for clinicians, researchers, and public health officials to communicate about mental health disorders. The manual is extremely influential in guiding clinical diagnoses, treatment plans, medication choices and protocols, insurance reimbursements, and research agendas [[12](#_ENREF_12)]. Another classification system, the ICD (currently as the 10th revision, ICD-10), is favoured in Europe and the UK for clinical diagnosis and reimbursement purposes, and informs the compilation of national and international health statistics [[4](#_ENREF_4)]. In New Zealand, whilst the ICD is used in generating statistical records, most clinicians use DSM in practice for diagnostic classification, including psychiatrists [[13](#_ENREF_13)]. However both classification systems appear to be employed by mental health nurses [[14](#_ENREF_14)], and there is variability in use in primary care due to their complexity and a lack of familiarity with them [[15](#_ENREF_15)].

In December 2012, the American Psychiatric Association's (APA) Board of Trustees approved the latest and fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), officially debuting in May 2013 at the APA's annual convention [[2](#_ENREF_2)]. The DSM-5 replaces the previous versions, DSM-IV [[16](#_ENREF_16)] and its text revision DSM-IV-TR [[17](#_ENREF_17)] which were used to define autism spectrum disorder (ASD) in the NZ ASD Guideline [[1](#_ENREF_1)][[2]](#footnote-2). In the guideline, ASD is used as an umbrella term to refer to a range of pervasive developmental disorders across the “autism spectrum” that affect communication, social interaction and adaptive behaviour functioning.

Development of DSM-5

The development of the DSM-5 represents the most far-reaching review ever undertaken for any DSM revision. The process began in 1999 when the APA and the National Institute of Mental Health (NIMH) sponsored the first of a series of research planning conferences for DSM-5. A DSM-5 Task Force was formed in 2007 and 13 work groups of 8-15 volunteer members were established to address specific areas for review. This included a DSM-5 Neurodevelopmental Disorders Work Group responsible for consideration of ASD which was chaired by Susan Swedo [[18](#_ENREF_18), [19](#_ENREF_19)].

Over a decade long process, hundreds of scientific articles were examined, secondary data analysis was conducted, feedback was considered and field trials were sponsored [[20](#_ENREF_20), [21](#_ENREF_21)]. A series of National Institute of Health (NIH) conferences were held including nearly 400 participants and resulting in 10 monographs.

A conference on autism was held in 2008 [[22](#_ENREF_22)]. In the first planning conference for DSM-V (as it was then known) in 1999, there was hope that many diagnoses could be identified by specific biological indicators such as brain scans or genetic tests, however during the revision process it was apparent that no reliable diagnostic markers for ASD were then available [[23](#_ENREF_23)].

An overarching vision for the DSM-5 was to develop a system for classifying mental disorders that would be applicable across geographical and cultural boundaries. To ensure the participation of investigators from all parts of the world, each conference had two co-chairs, one drawn from the US and another from outside the US. Approximately half of the experts invited to serve on the work groups were from outside the US and half of the conferences were convened outside the US [[19](#_ENREF_19)]. A multi-national DSM-5 field trial was conducted in routine clinical practice settings across the US, Canada, Australia and the UK [5].

In an unprecedented move for the DSM, draft criteria for the 5th revision were posted three times on the DSM-5 Web site to obtain public critique and input [5]. The drafts drew over 10,000 comments each considered and evaluated by the work groups [[18](#_ENREF_18)]. On several occasions the APA released public responses to “open letters” in efforts to correct perceived “misinformation” and defend the rigour of their processes [[18](#_ENREF_18)].

Controversy in release of the DSM-5

A major change in the DSM-5 is the re-classification of autism as a single spectrum disorder without distinct subtypes such as PDD-NOS, CDD and Asperger syndrome. This has attracted much attention in the academic, advocacy and public media. Fears have been raised that the DSM-5 will exclude from the diagnosis of ASD many people previously meeting criteria, thereby cutting them off from services and support. One researcher concluded emotively that “abandoning criteria that have been in worldwide use for decades” (the DSM-IV) is “neither scientifically or morally justified” [[24](#_ENREF_24)]. Alarming media headlines, petitions opposing the changes [[25](#_ENREF_25)] and an “Occupy APA” protest [[26](#_ENREF_26)] have contributed and responded to a public perception that a change in nomenclature may lead to the actual disappearance of conditions such as Asperger syndrome [[27](#_ENREF_27)].

Questions have also been raised about the independence of work group members, an alleged influence of pharmaceutical companies and concerns about confidentiality clauses. Beyond the revisions themselves, the British Psychological Society called for a paradigm shift away from the use of “outdated disease models” to classify clusters of symptoms as distinct disorders [28, [29](#_ENREF_29)].

In the absence of biological markers, the definition of mental disorders in the DSM continue to be refined, debated and tested. Amidst these passionate discussions the APA has advised that the DSM-5 should be considered a “living document” which will be revised online following its publication [[18](#_ENREF_18)].

1.2 DSM-IV criteria for diagnosing ASD subtypes

Autism was first officially recognised in the third edition of the DSM published in 1980 [[30](#_ENREF_30)]. In the latest revision of the fourth edition of the manual, DSM-IV-TR [[17](#_ENREF_17)], pervasive developmental disorders (PDD) consist of five subtypes: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder (CDD), Asperger's Disorder and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). The term Autism Spectrum Disorder has commonly come to refer to these PDD with the exception of Rett’s Disorder and sometimes CDD [[31](#_ENREF_31)]. Details of criteria for ASD in DSM-IV-TR are presented in **Appendix 3.**

Criteria for diagnosis for autism disorder in DSM-IV-TR include symptoms in three behavioural domains. This “triad of impairments” includes:

* impairment in social interaction
* deficits in communication, and
* restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities.

There are 12 symptom criteria relating to behavioural impairments, four in each of the three behavioural domains. To meet criteria for a Pervasive Developmental Disorder, delays or abnormal functioning need to be met in at least one of the three areas of impairment. Tighter criteria for autistic disorder require at least 6 criteria from the three areas of impairment, at least 2 from social interaction, and one each from the communication and restricted interests domains. Delays or abnormal functioning need to be evident in at least one domain before the age of 3 years.

Under DSM-IV-TR criteria, Asperger syndrome (Asperger’s disorder) has the same diagnostic criteria as autistic disorder but without clinically significant delays in early language development or cognitive development.

Pervasive Developmental Disorder - not otherwise specified (PDD NOS) has the least rigorous requirements for diagnosis under DSM-IV-TR. No specific number of symptoms are required to be met but a person needs to display severe social impairment in the development of reciprocal social interaction associated with communication deficits or stereotyped behaviors [[17](#_ENREF_17), [21](#_ENREF_21)].

1.3 DSM-5 criteria for diagnosing ASD

This section describes the revised criteria for ASD under the latest version of the DSM. Further details are presented in **Section A4.1** of **Appendix 4.**

Differences to the diagnostic criteria relating to autism spectrum between DSM-IV-TR and DSM-5 are summarised in **Table 1.1**.

Subtypes subsumed under a single diagnosis

In the DSM-5 [[2](#_ENREF_2)], four PDD subcategories specified in DSM-IV of autistic disorder, Asperger's disorder (syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS) are now subsumed into the one broad category of autism spectrum disorder. The subtype terms will no longer be used diagnostically under the DSM-5.

The PDD subtype Rett’s Disorder (syndrome) is excluded from the new ASD category. This is because the DSM focuses on disorders that can be defined behaviourally, without a molecular or biological test [[32](#_ENREF_32), [33](#_ENREF_33)]. Rett’s syndrome is a single gene neurological disorder in which those with the condition may go through a phase of social impairment, language regression and repetitive motor mannerisms resembling autism [[34](#_ENREF_34)].

Terminology has also changed. The name pervasive developmental disorder (PDD) has now been changed to Autism Spectrum Disorder (ASD). The term “mental retardation” has been replaced with the term “intellectual disabilities”.

Combining communication and social interaction domains

A further key change is that the three behavioural domains specified in the DSM-IV-TR (impairments in social interaction, deficits in communication, and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities) are now collapsed into two domains (i.e., a triad to a dyad of impairments). In the first, communication and social interaction have been combined as social communication or social reciprocity (criterion A). The second domain relates to restricted, repetitive patterns of behaviors (criterion B). It is understood that movement from three dimensions of behaviour to two has also occurred in the proposed ICD-11 diagnostic framework currently under development [[35](#_ENREF_35)].

Symptoms

Number of criteria

The number of symptoms within the domains has been streamlined from 12 to 7. For a diagnosis of ASD, all 3 criteria on the social-communication domain must be met and 2 of 4 criteria in the restricted interest domain must be present. Details of the criteria are presented in **Appendix 4 (Section A4.1**).

Notably, behaviours in this domain do not have to be currently present, they may be present only in history.

Sensory abnormalities

Unusual sensitivity to sensory stimuli was not considered a core feature of autism in previous DSM versions, but in DSM-5 they are included as a diagnostic symptom within the restricted, repetitive patterns of behaviour, interests, and activities domain:

Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects) [[2](#_ENREF_2)].

Symptom severity

Dimensional elements have been introduced which give an indication of how much a condition affects an individual. This will help identify how much support and in what areas of function an individual needs. The aim is to better capture the spectrum nature of the disorder, and reflect individual variations with respect to intensity and duration of symptoms, degree of impairment, and the distress they cause [[33](#_ENREF_33)].

Under the DSM-5, the diagnosis is accompanied by an indication of the level of symptom severity, graded according to the level of support required. Both language levels and intellectual functioning are imporant determinants of severity levels, as seen in the coding guide presented in **Appendix 4 (Section A4.2).** The 3-point scale is as follows:

1. mild - requiring support

2. moderate - requiring substantial support

3. severe - requiring very substantial support

Symptom onset

An additional change in the DSM-5 is the removal of the requirement that symptoms be evident before the age of 36 months. The criterion for symptom onset (Criterion C) has been extended with a more open definition such that:

Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

Impairment in functioning

A new criterion (Criterion D) has been added to the diagnosis of ASD such that the constellation of symptoms together must “cause clinically significant impairment in social, occupational, or other important areas of current functioning”.

Ruling out alternative diagnoses

A final criterion (Criterion E) notes that intellectual disability (intellectual developmental disorder) or global developmental delay may be better explanations for behavioural disturbances observed. In order to apply comorbid diagnoses of autism spectrum disorder and intellectual disability, it is specified that social communication should be below that expected for general developmental level.

Clinical specifiers

In addition, people diagnosed with ASD are described with relevant “clinical specifiers” which reflect personal characteristics. Specifiers for ASD include the following (for further information, see **Appendix 4, Section A4.1)**:

* with or without accompanying intellectual impairment
* with or without accompanying language impairment
* associated with known medical or genetic condition or environmental factor
* associated with another neurodevelopmental, mental, or behavioural disorder
* with catatonia
* onset (eg with regression) is to be described.

In the new overarching category of ASD, it is assumed that delays in language are neither unique to the autism spectrum nor universal to it; delays in language will affect an individual's clinical presentation but is not a defining diagnostic autistic spectrum criterion [[36](#_ENREF_36)].

Co-morbidities

Under DSM-IV-TR, a person couldn’t be diagnosed together with other conditions, including attention-deficit/hyperactivity disorder (ADHD), stereotyped movement disorder and psychiatric conditions such as anxiety states and schizophrenia. This limitation has been removed in DSM-5.

Structure

An intention of DSM-5 is to ensure greater harmony with the International Classification of Diseases (ICD) system. For example, the chapter structure of DSM now begins with those in which neurodevelopmental influences produce early-onset disorders in childhood [[20](#_ENREF_20)]. This cluster reflects disorders of neurodevelopment rather than a “childhood disorders” cluster. It comprises disorders subcategorised in DSM-IV and ICD-10 as Mental Retardation; Learning, Motor, and Communication Disorders; and Pervasive Developmental Disorders. A review of the literature found that the Neurodevelopmental cluster is largely characterised by the role of genetic factors; early age of onset; a continuing course; within-cluster co-morbidity; and the salience of cognitive symptoms [[37](#_ENREF_37)].

Cross-cutting assessments

The DSM-5 suggests a range of online “emerging measures” of dimensional assessment, including patient/informant- and clinician-completed measures developed for clinical use and research. It is noted that these measures are intended to be used to enhance clinical decision-making and not as the sole basis for making a clinical diagnosis. See **Appendix 5** for further details.

The measures, included in Section III of the DSM-5, include the following:

* So-called “cross-cutting” tools which can be applied across disorders to assess symptom domains that are relevant to most, if not all, mental disorders, such as mood, anxiety, sleep, and cognition. It is envisioned that these patient assessment measures be administered at an initial patient interview and to monitor treatment progress with the aim of enhancing clinical decision-making. Level 1 is a brief survey, and Level 2 provides a more in-depth assessment for when a particular domain is endorsed.
* If criteria for a diagnosis (such as ASD) is fulfilled, a third level of dimensional assessment can help establish its severity, with assessment corresponding closely to criteria that constitute the disorder definition.
* The World Health Organization Disability Assessment Schedule, Version 2.0 (WHODAS 2.0) assesses a person’s ability to perform activities in six areas: understanding and communicating; getting around; self-care; getting along with people; life activities (e.g., household, work/school); and participation in society[[3]](#footnote-3).
* The Personality Inventories for DSM-5 measure maladaptive personality traits in five domains: negative affect, detachment, antagonism, disinhibition, and psychoticism[[4]](#footnote-4).
* Other emerging measures include the Early Development and Home Background (EDHB) form, which assesses the early development and past and current home background experiences of a child receiving care, and a range of cultural assessment measures. These include the Cultural Formulation Interview (CFI) which obtains information about the impact of culture on key aspects of an individual’s clinical presentation and care, and an informant version for family members or caregivers. A further range of 8 Supplementary Modules provide more comprehensive cultural assessment of the various CFI domains.

Social (Pragmatic) Communication Disorder

A new disorder category outside of the autism spectrum has been created called “Social (Pragmatic) Communication Disorder” (SCD) (see **Appendix 4, Section A4.3** for details). There are two differentiating factors in diagnosing SCD over ASD.

First, children with social communication disorder must have persistent difficulties in pragmatics and/or the social use of verbal and non-verbal communication in natural contexts. Further, these would have to impair interpersonal relationships and social comprehension that cannot be explained by having more basic language difficulties (e.g., deficits in sentence structure, grammar, or general cognitive ability) or intellectual disability. To meet criteria for diagnosis, deficits in social communication also need to be evaluated as significantly and negatively influencing communication, social involvement, academic achievement, or occupational performance.

Second, the presence of fixated interests and repetitive behaviours is an exclusionary criterion for social communication disorder. The presence of repetitive behaviours is therefore crucial for the differential diagnosis of ASD [[38](#_ENREF_38)].

1.4 Recommendations in the ASD Guideline potentially impacted by DSM-5

Several areas across the current NZ ASD Guideline could be potentially affected by this topic, particularly in the diagnosis and assessment sections. Revisions may come in the form of changes to each relevant recommendation, and/or a summary statement regarding how to read all references to a change (such as removal of terms Asperger syndrome and PDD-NOS when refered to diagnostically).In the current ASD Guideline [[1](#_ENREF_1)], 5 recommendations potentially affected by the DSM-5 are presented in **Table 1.2**.

Table 1.2. Guideline recommendations relevant to diagnostic classification of ASD [[1](#_ENREF_1)]

|  |  |  |
| --- | --- | --- |
| Original Reference | Original Recommendation | Grade |
| Good practice point 1.3.5 | Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary. | **✔** |
| 1.2.5 | Standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be used. | **B** |
| 1.2.6 | Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing people with ASD and take these limitations into account when forming opinions and reporting results. | **C** |
| 1.2.7 | The assessment of intellectual, adaptive and cognitive skills associated with autism, Asperger syndrome and ASD should be seriously considered and, where possible and appropriate, formally assessed. | **B** |
| 6.2 | Education and training of local health care professionals in the administration of standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be provided. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established. | C |
| 6.3 | Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population. | C |

**Note**: criteria used for grading the recommendations are reproduced in **Appendix 1** (Table A1.2).

1.5 Research objectives

The current review updates evidence on diagnostic classification of ASD evident in the development and publication of the DSM-5 and the implications of the changes for the ASD Guideline [[1](#_ENREF_1)].

The objectives of this review were to:

* systematically identify, select and summarise evidence published since January 2004 relating to changes to the diagnostic criteria of ASD in the DSM-5; and to
* consider this evidence as it impacts on the original ASD Guideline [[1](#_ENREF_1)], including revision of existing recommendations or developing new ones.

The research question considered is: "What are the implications for the NZ ASD Guideline of the DSM-5’s changes to diagnostic classification relevant to ASD?

1.6 Search strategy

The original searching for the ASD Guideline [[1](#_ENREF_1)] was performed in July 2004. To be consistent with earlier updates produced for the Living Guideline Group, the search was limited to articles published in the English language on or beyond January 1 2004. However as the DSM-5 wasn’t publicly released until May 2013, articles of most relevance were those published in the last three years.

The search strategy had three components:

* core research material from the APA’s dedicated website, [www.dsm5.org](http://www.dsm5.org) ;
* empirical studies, reviews, commentaries and discussion papers identified from bibliographic and review databases; and
* position statements and featured commentaries from prominent autism websites.

Fourteen bibliographic, health technology assessment and guideline databases were included in the systematic search. The database searching was conducted in May 2013 and updated on 9 August 2013. References of retrieved articles were also cross-checked to identify additional articles.

Full details of review methods including search strategy, review synthesis and the process of revising recommendations are presented in **Appendix 1.**

1.7 Review synthesis

The review provides a narrative, critical synthesis of sourced material as it relates to the changes in the diagnostic classification of ASD presented in the DSM-5 and potential implications for the ASD Guideline’s recommendations.

Key areas included in the review are:

* Summary of DSM-5’s diagnostic classification of ASD
* Rationale for the DSM-5’s diagnostic classification of ASD
* Critical summary of empirical studies including APA’s field trials which relate to the development and validation of DSM-5’s diagnostic classification of ASD
* Summary of key issues identifed relating to the potential clinical, social and research impact of changes to DSM-5’s diagnostic classification of ASD.

2 Changes to diagnostic classification of ASD in the DSM-5

This chapter describes the findings of a review of the American Psychiatric Association’s (APA) DSM-5’s (Diagnostic and Statistical Manual of Mental Disorders – 5th edition) [[2](#_ENREF_2)] changes to diagnostic classification relevant to ASD, and a discussion of potential areas of impact.

2.1 Rationale for changes to diagnostic criteria

The rationale for the changes to the ASD criteria is summarised below. A key source for this is a commentary by Francesca Happé (2011) [[39](#_ENREF_39)], a member of the DSM-5 Neurodevelopmental Disorders Workgroup responsible for the revisions relevant to ASD.

Autism as a single spectrum disorder

The change to subsuming several PDD subtypes into a single diagnosis of autism spectrum disorder in the DSM-5 reflects a wide-spread consensus that autism is best considered as existing on a spectrum with variable manifestations across lifespan, gender, and intellectual level and/or language ability [[39](#_ENREF_39)]. This perspective is already consistent with the terminology used in the New Zealand ASD Guideline [[1](#_ENREF_1)].

By folding Asperger syndrome and PDD-NOS into the category of autism spectrum disorder, the DSM-5 aims to produce a clearer and simpler diagnostic system with improved recognition and diagnosis for those on the autism spectrum across all ages and ability levels. The main objective of the revision to the DSM relating to ASD was to increase the specificity of diagnosis, that is, make it easier to identify ASD as distinguished from other nonautistic disorders and to increase the stability of diagnosis over time [[40](#_ENREF_40)]. Having a single diagnostic entity avoids the problem of an individual receiving serial, or sometimes concurrent, diagnoses of PDD-NOS, autism and Asperger syndrome, depending on the clinician they see [[35](#_ENREF_35)] or maturation [[41](#_ENREF_41)]. Numerous studies have reported little qualitative difference between autism disorder and Asperger Disorder subtypes [[42](#_ENREF_42)].

Removal of Asperger syndrome and PDD-NOS as distinct disorder classifications from the DSM reflects multiple concerns regarding the reliability and application of these diagnoses when applying their DSM-IV diagnostic criteria. These include that: in clinical field trials, ASD experts frequently make different diagnoses based on the same presenting symptoms in the same individual; the boundary between Asperger syndrome and autism is not clear on a population basis; and in up to half of patient diagnoses of autism, Asperger's Disorder and PDD NOS are not stable within the same individual over time [[43](#_ENREF_43), [44](#_ENREF_44)].

A recent study by Lord and colleagues [[45](#_ENREF_45)] investigated clinical best estimate diagnoses for 2102 children with ASD across 12 university-based autism centers. Diagnoses (autism, Asperger syndrome, PDD-NOS) varied dramatically across sites, even when using the same diagnostic instruments and standardised procedures. Despite the characteristics of the children being similar, clinicians used non-ASD specific behavioral characteristics (such as hyperactivity), age and IQ to make diagnoses, with patterns of biases varying between sites. For example, in one site, children of more educated mothers were more likely to get an Asperger's Disorder diagnosis, even after controlling for the characteristics of the children.

The validity of distinct categories of ASD is also questioned in terms of outcome over time. A record-linkage study in Norway followed up 74 children with autism disorder and 39 with PDD-NOS. It found a lack of substantial differences in prognosis in terms of rates of disability pension award, marital status, criminality and mortality [[46](#_ENREF_46)]. Authors concluded that their findings support a dimensional description of ASD in line with the DSM-5.

Removal of Asperger’s Disorder as a diagnosis

Asperger's Disorder (Asperger syndrome) was first included as a categorical diagnosis in DSM-IV in 1994 [[16](#_ENREF_16)]. Asperger syndrome is a pervasive developmental disorder characterised by social impairments and focused, circumscribed interests and activities in the absence of significant language impairment and cognitive delay. In both the DSM-IV-TR [[17](#_ENREF_17)] and ICD-10 [[47](#_ENREF_47)] classification systems, the full criteria for autism disorder are not met.

Since its inclusion in DSM-IV there has been a dramatic increase in its recognition in children, as well as adults. Age of diagnosis of Asperger syndrome (AS) is relatively high, the mean age being 10-11 years of age [[48](#_ENREF_48)], and not infrequently occurs in adulthood. Asperger syndrome has remained a controversial diagnosis, being difficult to distinguish clinically from autism with normal intelligence, known as “high-functioning autism”. The DSM-5 changes to the autism spectrum attempt to solve the contentious issue of language delays being a unique characteristic of the autism spectrum but not Asperger syndrome [[36](#_ENREF_36)].

In the DSM-IV, a criteria for Asperger syndrome over those with “high functioning autism” with an equivalent developmental level or IQ is meeting expected language milestones in the first 3 years. However research suggests that these groups do not differ significantly, with very similar outcomes in adolescence and adulthood [[49](#_ENREF_49)]. Further, there has been no evidence of differential treatment response or aetiology, and claims for a distinct neurocognitive profile in Asperger syndrome have received mixed results. Taken together there is little evidence to support a diagnostic distinction between Asperger syndrome and high-functioning autism [[39](#_ENREF_39)].

Further, the criteria for Asperger syndrome in DSM-IV have been found to be flawed and hard to implement in practice, leading to confusion for individuals and parents [[50](#_ENREF_50)]. Asperger diagnosis requires establishing whether single words were spoken before 2 years of age and phrases by 3 years of age. This is difficult to determine, particularly given the older age of diagnosis.

In addition, the diagnosis of Asperger syndrome was intended to be applied only when criteria for autistic disorder were not met. However, several studies indicate that a high number of people with diagnoses of AS meet criteria for autism [[51](#_ENREF_51)].

The inclusion of Asperger’s Disorder in the DSM-IV gave recognition to the fact that people on the spectrum can have high IQ and good language. Happé [[39](#_ENREF_39)] suggests that the DSM-5 changes reflect that its time to reintegrate Asperger disorder with the rest of the spectrum and to demand the same level of respect and lack of stigma for individuals across the full range of manifestations of the spectrum.

Removal of PDD-NOS

Of the DSM-IV diagnoses, PDD-NOS is a residual category, is the most poorly defined and with poor agreement across clinicians in its diagnosis. It is far more commonly given than autistic disorder, creating a situation where atypical presentations are more common than typical ones [[51](#_ENREF_51)].

Such problems result in wide variation in the diagnosis of Asperger syndrome and PDD-NOS in practice. This is demonstrated in a study which showed that the best predictor of which ASD diagnosis a person received (Asperger syndrome, PDD-NOS, or autistic disorder) was which clinic the individuals went to, rather than any individual characteristic [[45](#_ENREF_45)].

Removal of Childhood Disintegrative Disorder

The reasons for removal of this group as a distinct disorder include that the condition rarely occurs, the defining behaviours after onset fall well within the spectrum of autism, and that the group can still be separately monitored through specifier codes of age and type of onset [[51](#_ENREF_51)].

Whilst these disorders (AS, PDD-NOS and CDD) are not reliably diagnosed or distinguished in clinical practice, the same studies suggest that clinicians show good agreement about who falls within the autism spectrum [[39](#_ENREF_39)].

Social communication disorder

A new classification of social (pragmatic) communication disorder (SCD) has been devised which sits outside of ASD as a separate and distinct diagnosis. SCD provides diagnostic coverage to people who present with deficiencies in pragmatics that interfere with communication, social functioning and learning, with onset in early childhood, but who do not the display repetitive and stereotyped behaviours of ASD [[33](#_ENREF_33)].

Concerns have been raised that many children currently receiving the diagnosis of PDD-NOS will not meet proposed DSM-5 criteria for ASD because of a lack of restricted/repetitive behavior [[52](#_ENREF_52)]. It is hoped that the new diagnosis of SCD will more clearly and accurately capture the pattern of impaired social and communication abilities seen in some individuals who previously would have met criteria for the largest PDD subgroup of PDD-NOS.

Triad to dyad

The change from a triad of three impairment domains to a dyad of two follows from combining of social interaction and communication domains in DSM-5. This change follows population-based twin studies and factor analyses involving people with ASD which have demonstrated that difficulties in social interaction and communication are part of the same domain [[21](#_ENREF_21), [53-56](#_ENREF_53)].

It has been argued that distinguishing the ‘social' and ‘communication' domains is somewhat arbitrary since communication is social and being social is communicating. Moreover, in the DSM-IV some very similar symptoms are covered by multiple criteria across the “social” and “communication” domains. For example, behaviours indicative of “poor socio-emotional reciprocity” are covered in three criteria - poor emotional reciprocity (social domain), lack of sharing enjoyment and interests (social domain), and poor reciprocal conversation (communication domain) [[57](#_ENREF_57)].

Symptoms

Symptom descriptors

Under DSM-5 the number of symptom criteria for ASD have been streamlined from 12 to 7 by merging criteria that overlapped or described similar behaviours (e.g., limited social-emotional reciprocity, limited sharing of interests, and reduced back and forth conversations are combined to one reciprocity symptom), and eliminating symptoms that are not speciific to ASD (such as delayed language development) [[33](#_ENREF_33)].

In the new manual, each criteria includes several examples of behaviours from across the lifespan that may indicate the presence of that symptom. The symptom descriptions are inclusive of both the very young as well as adults with ASD [[58](#_ENREF_58)]. These developmentally specific examples of behaviours provide flexibility for clinicians in identifying an individual’s symptoms which may manifest differently across the lifespan from toddlerhood to adulthood. This change addresses concerns that the DSM-IV criteria relating to ASD performed less well when diagnosing toddlers, pre-schoolers, adolescents, and young adults [[40](#_ENREF_40)].

Sensory abnormalities as a core feature of ASD

Under DSM-5, sensory abnormalities are newly included as a core, diagnostic symptom of the restricted, repetitive patterns of behaviour (RRB) domain. This change is based on empirical research finding that this symptom has sensitivity and specificity as a diagnostic criteria for ASD, and factor analytic evidence that places it in the RRB symptom dimension [[56](#_ENREF_56)]. This improves the relevance of the criteria to younger children with ASD, because sensory issues are common concerns in this population [[59](#_ENREF_59), [60](#_ENREF_60)].

Symptom onset

The time of diagnosis may be much later than the time of actual onset of a disorder. The DSM-5 acknowledges that ASD may not manifest itself fully in infancy because of difficulty in identifying early signs, poor parental recall, and minimal social demands made of children in the early years. As requirements for social abilities increase with age, social impairments become more apparent [[61](#_ENREF_61)]. For these reasons, the requirement for symptom onset before 3 years has been changed to “the early developmental period”.

Dimensional descriptors

Throughout DSM-5 a new approach is taken, complementing categorical diagnosis (ASD versus not ASD) with a dimensional aspect, such that the difference between ASD symptom levels are a matter of degree.

The overarching ASD diagnosis recognises the essential shared features of the autism spectrum while attempting to individualise diagnosis through dimensional descriptors or clinical specifiers. These measurements aim to ensure that the individual's level of impairment is identified and described, including severity of symptoms, level of language development, any concomitant intellectual or language difficulties, and other disorders such as attention-deficit hyperactivity disorder (ADHD), mood disorder, motor or sleep problems [[39](#_ENREF_39)].

Harmonisation with ICD-11

There have been efforts to harmonise the definition of mental disorders between the DSM and ICD systems since DSM-III [[30](#_ENREF_30)], with the incorporation of official ICD statistical code numbers referenced with relevant DSM diagnoses. Efforts to maintain, and where possible enhance, consistency of DSM and ICD revisions for clinical guidance have been made, despite their different publication dates, with ICD-11 slated for publication in 2015 [[4](#_ENREF_4)]. Collaborative efforts between the WHO and APA has been promoted through 13 joint international research conferences held between 2003 and 2008, “harmonisation meetings”, and cross membership of chairs and working groups [[4](#_ENREF_4), [34](#_ENREF_34)]. Nevertheless, some differences are likely to remain, including that the uncommon condition Childhood Disintegrative Disorder (CDD) has been removed from DSM-5 yet may be retained as a diagnosis in ICD-11 requiring further research [[51](#_ENREF_51)].

2.2 Reliability and validity of DSM-5 criteria for ASD

The DSM-5 manual lists the specific diagnostic criteria that have to be met for a diagnosis of autism speectrum disorder to be given. This process needs to be reliable (gives the same diagnosis is given for the same presenting symptoms) and valid (indicates which individuals have the condition and which don’t). Preliminary evidence investigating these aspects is summarised below.

Test-retest reliability

A diagnostic test is considered reliable to the extent that it can be understood and used by different clinicians in a consistent, replicable manner to lead to the same diagnosis for the same presentation of symptoms.

There are three major types of reliability assessments [[62](#_ENREF_62)].

1. **Intra-rater reliability** which requires that the same rater be asked to “blindly” review the same patient material two or more times.
2. **Inter-rater reliability** which requires that two or more different raters review the same patient material.
3. **Test-retest reliability** which requires that the same patients be observed separately by two or more raters within an interval during which the clinical conditions of the patients are unlikely to have changed.

Most medical reliability studies, including many DSM reliability studies, have been based on inter-rater reliability: two independent clinicians viewing, for example, the same checklist or interview for the same patient to determine a diagnosis. However, test-retest reliability best reflects the process of diagnosis in clinical decision making and that has been the focus of the DSM-5 field trials [[62](#_ENREF_62)].

The DSM-5 Field Trials [[4](#_ENREF_4), [63](#_ENREF_63), [64](#_ENREF_64)] were designed to obtain precise estimates of intraclass *kappa* (percentage agreement with chance agreement taken into account) as a measure of the degree to which two clinicians could independently agree on the presence or absence of selected DSM-5 diagnoses – test-retest reliability.

Large-intake clinical sites were identified (principally from academic or research centres) to draw a sample representative of the site's patient population. Consecutive patients visiting a site during the study were screened and stratified on the basis of DSM-IV diagnoses or symptomatic presentations. Patients were randomly assigned to two clinicians for a diagnostic interview, each prompted by a computerised checklist, and blind to any previous diagnosis. Two independent clinicians performed the diagnostic evaluations for each child, and the evaluations were performed within two weeks of each other.

Only two paediatric sites collected data on diagnosis of ASD (Massachusetts and California), involving children aged 6-17 years, who could communicate in English (independently or through a guardian), and who had been screened as being at high risk for ASD. Test-retest reliability for diagnosing ASD was “very good” (kappa=0.69, 95% CI 0.58-0.79). Good test-retest reliability results were also exhibited for the DSM-5’s cross-cutting measures [[64](#_ENREF_64)]. However, the trials did not include children under 6 years old or adults [[4](#_ENREF_4)] and sample size of participants from the two sites was very small (n=64). Some data on prevalence of ASD under the two versions of DSM-5 were also collected [[4](#_ENREF_4)], and these are discussed in the section on diagnostic accuracy below.

Construct validity

Factor structure

Several studies have investigated the construct validity of DSM-5’s conception of ASD as a single, continuous disorder with two dimensions of impairments (social communication and repetitive behaviour dimensions).

Using confirmatory factor analysis, latent class analysis and factor mixture modeling techniques (see **Glossary**), a number of studies in different populations have found that characteristics of ASD map best to a two-factor model of the DSM-5 (with distinct social communication and repetitive behavior dimensions) in line with the DSM-5 dyad of impairments, compared with other models. This has been observed in a sample of 708 verbal children and young people in the UK [[56](#_ENREF_56)], a large sample of 14,774 siblings aged 2-18 years [[53](#_ENREF_53)], and two studies of toddlers [[54](#_ENREF_54), [65](#_ENREF_65)]. In one of these [[65](#_ENREF_65)], results also supported the reorganisation of symptoms in the DSM-5. For example, unusual sensory interests and unusual intonation loaded onto the “repetitive/restricted language and behaviour” factor where it is placed in DSM-5.

Using latent profile analysis, six distinct phenotypic profiles were identified in a sample of 949 mainly cognitively able children (aged 6-18 years) with ASDs (that is, autism related PDDs) referred to two academic-based clinics in the Netherlands [[66](#_ENREF_66)]. Three of these were not completely in line with the proposed DSM-5 conceptualisation of autism, and were more likely to include cognitively able individuals with PDD-NOS. Almost one-third (30%) of the total PDD sample fell into the class with a SCD-like phenotypic profile. The authors suggest that SCD, once more clearly operationalised, might be a useful category.

Convergent and discriminant validity

Convergent and discriminant validity are both considered subcategories or subtypes of construct validity. Convergent validity refers to the degree to which a test/measure correlates with (or is related to) scores on other tests that are designed to assess the same construct. Whereas discriminant validity is the degree to which scores on a test do not correlate with scores from other tests that are not designed to assess the same construct (that is, the test can discriminate between dissimilar constructs).

According to the APA, DSM-5 field trials have evaluated the convergent and discriminant validity of the DSM-5 diagnoses with a paper currently in preparation (*personal communication,* Oct 25 2013, Alison Beale, DSM Research Associate).

Diagnostic accuracy

A key goal in developing diagnostic criteria for classifying a disorder is to make the criteria sensitive enough to diagnose those who have a disorder and specific enough to exclude those who don’t [[67](#_ENREF_67)]. Comparisons with (ideally) an independent “gold reference standard” permit reports of diagnostic accuracy in the form of “sensitivity” and “specificity”.

* **Sensitivity** is the ability of a test to identify correctly those who have the condition
* **Specificity** is the ability of the test to identify correctly those who do not have the condition

There has been a good deal of research activity across several countries investigating the diagnostic outcomes of the new (or in most cases, proposed) diagnostic changes presented in DSM-5 relating to ASD. The research has also been driven by concerns that the DSM-5 criteria are “tighter” and will lead to a reduction in the number of people receiving a diagnosis of ASD compared with the DSM-IV, particularly those who are higher functioning and verbally able. Alternatively, it has been suggested that more people may meet the critera of ASD than before because the diagnosis is now based not just on current symptoms but on an individual's history, and there is a new criterion relating to sensory abnormalities not present in previous versions of the DSM [[21](#_ENREF_21)].

There has been a raft of studies comparing the number of people diagnosed with ASD under DSM-IV criteria with those diagnosed with ASD according to DSM-5 criteria. See **Table 2** for a summary of comparative studies, ordered alphabetically by first author.

Several record review studies have accessed data from DSM-IV-TR checklists and interview notes and retrospectively applied DSM-5 criteria in order to compare diagnostic outcomes between the two versions. Two small studies using this method found similar results for samples of children with ASD according to DSM-IV criteria. An exploratory study by **You and colleagues** [[68](#_ENREF_68)] found that 60% of 135 toddlers with a PDD met DSM-5 criteria for ASD, whereas 63% did so in a Canadian study of 131 older children aged 2-12 years by **Taheri et al** [[25](#_ENREF_25)]. The Canadian study also found that those diagnosed with PDD-NOS, and those with higher IQ, were less likely to be diagnosed under DSM-5 [[25](#_ENREF_25)].

A small Finnish study by **Mattila et al** [[69](#_ENREF_69)] compared diagnoses using DSM-IV criteria with those using draft DSM-5 criteria in 82 8-year-old children (from an epidemiological sample of 5,484). Only 12 (46%) of the 26 children with DSM-IV diagnosed ASD and an IQ of at least 50 were identified as having ASD according to draft DSM-5 criteria. None of 11 participants with Asperger syndrome were identified under DSM-5.

Table 2. Studies comparing diagnosis of ASD using DSM-5 with DSM-IV-TR

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Study | Region | Sample | Source of sample | Instruments Used | Results | Limitations |
| Frazier et al [[53](#_ENREF_53)] | US | 14,744 siblings (8,911 with autism, 5,863 non-ASD siblings), aged 2-18 years | Family-selected internet registry (Interactive Autism Network) | Mapped caregiver rated SRS and SCQ to draft DSM-5 criteria | DSM-5 had lower sensitivity (Se=0.81 vs 0.95) but greater specificity (Sp=0.97 vs 0.86) than DSM-IV | Early DSM-5 criteria, self-selected sample, reliance on caregiver reports only with no direct assessments |
| Gibbs et al [[70](#_ENREF_70)] | Australia | 132 children & youth (111 with ASD, 26 non-ASD) aged 2-16 years | Referred to tertiary clinic for initial evaluation | ADOS (clinician rated), ADI-R (rated by caregiver) | 77% of participants with DSM-IV rated ASD were diagnosed with ASD by DSM-5, Specificity=100% | Small clinical sample, ADOS and ADI-R are DSM-IV based tools, DSM-5 diagnosis always followed DSM-IV diagnosis by the same clinician based on the same interview data |
| Huerta et al [[6](#_ENREF_6)] | North America | 5,143 children and adolescents, (4453 with PDD, 690 non-PDD) aged 2-18 years | Data sets from family genetics study, university and autism databank | ADI-R and ADOS mapped to DSM-IV and DSM-5 criteria. | Based on ADI-R only, Se=0.91 for DSM-5 vs 0.91-0.98 for DSM-IV (depending on diagnosis). Specificity was low for DSM-5 (Sp=0.53) and DSM-IV (Sp=0.24-0.53 for DSM-IV) | More severe clinical sample, retrospective review, ADOS and ADI-R are DSM-IV based tools |
| Mattila et al [[69](#_ENREF_69)] | Finland | 82 (26 with ASD and IQ≥ 50) of 8-year-old children | Screened epidemiological sample diagnosed with DSM-IV criteria | ADOS, ADI-R, | 46% of participants with DSM-IV diagnosed ASD were diagnosed with ASD by DSM-5 | Not clear how small sample identified from cohort, ADOS and ADI-R are DSM-IV based tools, early DSM-5 criteria, no independent reference standard |
| Matson, Belva et al [[71](#_ENREF_71)] | US | 289 adults (156 with ASD, 133 with developmental disabilities) aged 18-88 years | Residents from two developmental centres | DSM-IV-TR/ICD-10 Checklist | 64% of adults with DSM-IV diagnosed ASD were diagnosed with ASD by DSM-5 | Sample from residential developmental disorder clinic, DSM-IV checklist used to identify DSM-5 criteria, 41 participants excluded [[5]](#footnote-5) |
| Matson, Kozlowski et al [[72](#_ENREF_72)] | US | 2,712 toddlers, (795 with ASD, 1926 non ASD) aged 17-36 months | EarlySteps (early intervention for at risk for developmental disabilities) | Clinical judgement using diagnostic algorithms from DSM-IV-TR and DSM-5 and review of M-CHAT, BDI-2 | 52% of toddlers with DSM-IV ASD were diagnosed with ASD by DSM-5 | No independent reference standard |
| Mayes et al [[73](#_ENREF_73)] | US | 125 children (93 with ASD, 32 with clinical nonautistic disorder) aged 1-16 years | 2 clinics: academic child psychiatry practice site, & hospital-based paediatrics clinic | Clinical judgement based on parent interview, records, completion of CASD and PBS by parent and teacher, and direct observation. | Reference diagnosis established by clinical diagnosis and CASD. DSM-5 had lower sensitivity (Se=0.75 vs 0.89) and similarly high specificity (Sp=1.00 vs 0.97) compared with DSM-IV. | Small, clinical sample, one diagnostician not blind to diagnosis by comparison criteria. |
| Study | Region | Sample | Source of sample | Instruments Used | Results | Limitations |
| Mazefsky et al [[74](#_ENREF_74)] | US | 498 high-functioning people with ASD, aged 5-61 years | Research participants from earlier studies | ADOS, ADI-R | Sensitivity: 93% with DSM-IV diagnosed and clinically confirmed ASD were diagnosed by DSM-5 using combined ADOS/ADI-R criteria. Specificity not reported | Limited to verbally fluent, high functioning people, additional information from ADI-R items needed to reach 93% sensitivity |
| McPartland et al [[31](#_ENREF_31)] | US | 933 (657 with ASD, 276 non-autistic disorder) aged 1-43 years | Multicentre DSM-IV field trial database with high reliability | DSM-IV field trial checklist (algorithm of selected items mapped to correspond with proposed DSM-5 criteria) | Sensitivity: 61% of participants with ASD met DSM-5 criteria.  Specificity: 95% | Included only 48 DSM-IV subjects with Asperger syndrome, selected historical DSM-IV checklist data to apply draft DSM-5 criteria |
| Regier et al [[4](#_ENREF_4), [75](#_ENREF_75)] – DSM-5 field trial | US | 64 children at high risk for ASD aged 6-17 years | Two sites: a specialist medical clinic, and university-based clinic | Clinical judgement, DSM-IV and DSM-5 checklists | 95% of participants with DSM-IV diagnosed ASD were diagnosed with ASD by DSM-5 | Small sample, DSM-IV diagnoses identified retrospectively |
| Taheri & Perry [[25](#_ENREF_25)] | Canada | 131 children with ASD aged 2-12 years | Retrospective file review | CARS, DSM-IV checklist | 63% of participants with DSM-IV diagnosed ASD were diagnosed with ASD by DSM-5 | Small sample of children with ASD only, retrospective file review, no Asperger syndrome patients, DSM-IV checklist used to apply draft DSM-5 criteria, no independent reference standard |
| Wilson et al [[57](#_ENREF_57)] | UK | 150 intellectually able adults (13 with ASD by ICD-10) aged 18-65 years | Specialist clinic | ICD-10R supplemented by ADOS-G and/or ADI-R and interview | 78% of participants with DSM-IV diagnosed autism or Asperger’s Disorder were diagnosed with ASD by DSM-5 | Used assessment by ICD-10 and DSM-IV based checklists as reference standard. |
| Worley & Matson [[76](#_ENREF_76)] | US | 360 children and adolescents (180 with ASD, 166 non-ASD) aged 3-16 years | Advocacy and support groups, schools and an outpatient clinic | Caregiver rated symptom checklists | 67% of participants with DSM-IV diagnosed Autism or Asperger’s Disorder, and 56% with ICD-10R diagnosed ASD, were diagnosed with ASD by DSM-5 | Selection biases possible, care-giver rated DSM-IV checklist used to identify DSM-5 criteria, no independent reference standard |
| You et al [[68](#_ENREF_68)] | US | 135 with ASD aged 18-56 months | Retrospective file review | DSM-IV checklists, play observation, as presented in medical records | 60% of participants with DSM-IV diagnosed ASD were diagnosed with ASD by DSM-5 | Small sample of children with ASD only, retrospective file review, DSM-IV checklist used to apply draft DSM-5 criteria, no independent reference standard |
| **Key**: ADI-R=Autism Diagnostic Interview-Revised, ADOS=Autism Diagnostic Observation Schedule; ASD=autism spectrum disorder; BDI-2=Battelle Developmental Inventory, 2nd Edition; CARS=Childhood Autism Rating Scale; CASD=Checklist for Autism Spectrum Disorder; M-CHAT=Modified Checklist for Autism in Toddlers; NOS=not otherwise specified; PBS=Pediatric Behavior Scale; PDD=pervasive developmental disorder; Se=Sensitivity; Sp=Specificity; SCQ=Social Communication Questionnaire; SRS=Social Responsiveness Scale; UK=United Kingdom; US=United States of America | | | | | | |
| **Note:** Table layout after Lohr & Tanguay, 2013 [[77](#_ENREF_77)] | | | | | | |

A series of studies have been conducted by **Matson and colleagues** in a range of populations and using different diagnostic measures. Of individuals diagnosed with ASD under DSM-IV, 52% of a large sample of toddlers with developmental disabilities [[72](#_ENREF_72)], 67% of children and adolescents [[76](#_ENREF_76)], and 64% of adults [[71](#_ENREF_71)] met the criteria for ASD under DSM-5 criteria. Several studies for this team have found that individuals meeting proposed DSM-5 criteria tended to have more severe impairments than individuals meeting DSM-IV criteria [[71](#_ENREF_71), [76](#_ENREF_76), [78](#_ENREF_78)], suggesting that the higher functioning people may have been less likely to be diagnosed under the new manual. Similarly a study of toddlers found that children meeting DSM-5 criteria for ASD had more challenging behaviours than those who only met DSM-IV criteria [[79](#_ENREF_79)].

In the United States a study by **McPartland et al** [[31](#_ENREF_31)] reanalysed data from the original 1993 DSM-IV field trial evaluating clinical diagnoses of PDDs. The study evaluated sensitivity and specificity by re-scoring the DSM-IV symptom checklist items in order to rate the proposed (draft) DSM-5 algorithm. When this was applied to a data set of 933 people, 657 of whom were diagnosed with ASD by DSM-IV criteria, 60.6% of those with a clinical diagnosis of an ASD met the early DSM-5 criteria for ASD. Specificity was very high at 94.9%. The sensitivity of the DSM-5 criteria was particularly low for people diagnosed with Asperger syndrome (25%), PDD NOS (28%) and people with IQ at or over 70 (46%). Sensitivity and specificity did not vary significantly as a function of age or gender. The authors concluded that the new DSM criteria could have detrimental clinical and research effects.

The reported results and conclusion garnered significant media attention, raising alarm about the potential for reduced access to services. It also drew debate and criticism, drawing an editorial by the relevant DSM work group in which several methodological flaws of the study were raised [[80](#_ENREF_80)]. Criticisms included that archival data was used, such that the sample were initially identified by DSM-III or DSM-III-R criteria on a convenience sample which included people refered on suspicion of having autism and therefore skewed toward individuals with ASD. Other criticisms, common to other studies on this issue, including that the symptom checklist used was not originally designed for the DSM-5 and therefore did not collect all the information necessary to evaluate the proposed criteria [[40](#_ENREF_40)]. In such retrospective approaches, unless very comprehensive assessments are accessed, there may be insufficient information to determine details such as the history of restrictive and repetitive behaviours, which can lead to some individuals being seemingly missed in the comparison of diagnostic criteria [[35](#_ENREF_35)].

A number of recent studies have reported somewhat higher sensitivity estimates for DSM-5 criteria. These studies have tended to combine a range of sources of information to determine the DSM-5 criteria, such as the well validated parent report measure of ASD symptoms (Autism Diagnostic Interview–Revised, ADI-R) and the clinical observation instrument (Autism Diagnostic Observation Schedule, ADOS), clinical interview, observation and other records.

In a large sampled study of 14,744 siblings (8,911 with autism, 5,863 non-ASD siblings) aged 2-18 years, **Frazier and colleagues** [[53](#_ENREF_53)] mapped caregiver-reports of autistic symptoms to draft diagnostic criteria for DSM-5. Comparing DSM-5 guided dagnoses with DSM-IV diagnoses, results for the latest revision of the DSM showed greater specificity to reduce false-positive diagnoses (0.97 vs. 0.86) and moderately lower sensitivity (0.81 vs. 0.95), especially with females.

Data from two sites of the APA-sponsored DSM-5 field trials (described earlier with respect to test-retest reliability) also collected data on whether children identified as having ASD under DSM-IV retained their diagnosis when diagnosed prospectively according to DSM-5 criteria [[4](#_ENREF_4)]. According to a report by working party chair Susan Skuse, “roughly 95%” of the children did [[40](#_ENREF_40)]. The published results by **Regier and colleagues** state that there was no significant change in prevalence at one site between the two DSM versions: DSM-IV=0.23 vs DSM-5=0.24 (95% CI=0.20–0.30), but there was somewhat of a decrease in the DSM-5 autism spectrum rates at the second site: DSM-IV=0.26 vs DSM-5=0.19 (95% CI=0.15–0.24). When diagnoses for ASD and social (pragmatic) communication disorder were combined, the DSM-5 prevalence estimates improved, being 0.28 and 0.24 at the two sites, respectively [[4](#_ENREF_4)]. The study is limited by having a sample that is small (n=64), included no adults, was predominantly Causacian, and was drawn from academic or specialist clinics that may not generalise to diagnosis among a broader population.

An Australian prospective study by **Gibbs et al** [[70](#_ENREF_70)] of 132 young people involved the same clinician using the same information using clinician and caregiver checklists (ADOS and ADI-R) to record two diagnostic outcomes, one using DSM-IV-TR criteria followed by one using proposed DSM-5 criteria. The study found that 77% of young people with ASD under DSM-IV criteria met DSM-5 criteria for ASD, and no person without ASD under DSM-IV criteria was diagnosed as having ASD under DSM-5 criteria (i.e., a specificity of 100%). Sensitivity of diagnosis under DSM-5 was reduced for people with a DSM-IV diagnosis of PDD-NOS (only 50% meeting DSM-5 criteria for ASD).

The APA’s fact sheet [[81](#_ENREF_81)] about the DSM-5 relating to ASD refers (only) to a more recent, large trial as the most comprehensive assessment of the DSM-5 criteria for ASD. In this trial, **Huerta et al** [[6](#_ENREF_6)] analysed three large databases including more than 5000 children and adolescents aged 2 to 17 years: 4,453 children with DSM-IV diagnoses of ASD, and 690 people with non-ASD diagnoses (e.g., language disorder, attention deficit hyperactivity disorder). Items from the care-giver reported ADI-R and the clinical observation ADOS instruments were matched to DSM-IV and DSM-5 criteria and then used to evaluate sensitivity and specificity when compared with clinical best-estimate diagnoses as the reference standard.

The study found that most children who received a diagnosis of one of the ASDs under the DSM-IV would receive the diagnosis of ASD under the DSM-5. When only parent-rated symptoms (using the ADI-R) were used to identify children with ASD, the sensitivity of the DSM-5 criteria (0.91) was as high as that of the DSM-IV criteria for autistic disorder (0.91). DSM-IV criteria for Asperger syndrome and PDD-NOS had somewhat higher sensitivities (0.97 and 0.98, respectively). Only 75 of 5,143 participants met criteria for the newly classified Social Communication Disorder (SCD). Notably, there were high sensitivity rates in subgroups such as girls, children under 4 years, and children with language impairments. These finding are notable given that a goal of the DSM-5 revisions was to make them more sensitive to autism in groups that are often under-diagnosed, such as girls [[67](#_ENREF_67)].

Both the DSM-IV and DSM-5 criteria for ASD have a moderate ability to correctly identify children without ASD. There was similar, fair specificity (0.53) for autistic disorder for both DSM-IV and DSM-5 classification systems, but the DSM-IV criteria for Asperger syndrome and PDD-NOS had lower specificity (0.34 and 0.24, respectively). The overall accuracy of nonspectrum classification (specificity) made by DSM-5 was slightly better than that of the DSM-IV criteria [[82](#_ENREF_82)]. When combining clinical observation with parental report of symptoms, the sensitivity of the proposed DSM-5 criteria remained about the same (0.90) but specificity was improved (from 0.53 to 0.63).

The authors acknowledge limitations of their research including clinical samples, reliance on retrospective review of archival data and symptom counts (based on DSM-IV criteria) rather than prospective clinical diagnosis. Another criticism was that only a small number of participants (n=238) had Asperger syndrome (AS) (of N=4,453), which may have lead to an overestimate of sensitivity and specificity [[24](#_ENREF_24)]. Responding to this criticism, the authors said that similar results were obtained in separate analyses for subjects with AS and with PDD-NOS when both parental report and clinical observation were used [[83](#_ENREF_83)].

Three studies have been published in 2013 reporting sensitivity of between 0.75 and 0.93 for DSM-5.

A small study by **Mayes et al** [[73](#_ENREF_73)] considered diagnostic accuracy for 125 children (93 with ASD and 32 with nonautistic disorders such as ADHD) aged 1-16 years sourced from two specialist clinics. The sensitivity and specificity of diagnosing ASD was determined using DSM-IV and DSM-5 criteria as compared with clinical judgement as a reference standard. This judgement was based on parent interview, clinical observations, a teacher/caregiver report, and a validated assessment tool (the Checklist for Autism Spectrum Disorder). The CASD considers autism as a single spectrum as opposed to PDD subtypes, and includes assessment of sensory problems.

Diagnosis using DSM-5 criteria was found to have lower sensitivity than DSM-IV (Se=0.75 compared with 0.89) but similarly high specificity (Sp=1.00 vs 0.97). Sensitivity was universally very high for diagnosing children with autism (low and high functioning) (DSM-5=98%, DSM-IV=100%) but only 27% of children with PDDNOS were identified by the DSM-5 as having ASD. Further, the unidentified children had significant autism symptoms on an autism severity measure compared to controls, replicating findings of several other studies [[72](#_ENREF_72), [76](#_ENREF_76), [84](#_ENREF_84)].

In one of the few studies including adults, **Wilson et al** [[57](#_ENREF_57)] investigated whether ASD diagnostic outcome varied when DSM-5 was used compared to diagnoses under ICD-10R and DSM-IV-TR in a clinical sample of 150 intellectually able adults in the UK. Diagnoses were retrospectively established with reference to clinical notes and instruments (ICD-10R, ADOS, ADI-R). Of those diagnosed with Autistic Disorder/Asperger syndrome on DSM-IV-TR, 78% met DSM-5 ASD criteria, with specificity of 97%. Of those diagnosed with ASD by ICD-10R, only 56% met DSM-5 criteria for ASD with an additional 14% meeting criteria for SCD.

Sensitivity of DSM-5 was significantly increased by rating “uncertain” criteria as “present”, without sacrificing specificity. The authors acknowledge that prospective use of DSM-5 criteria in the clinic after full training and with careful consideration of missing or uncertain symptom information may improve sensitivity without adversely affecting specificity.

Finally, the study by **Mazefsky and colleagues** considered 498 high functioning, verbally-fluent people with DSM-IV defined and clinically confirmed ASD (aged 5–61 years) who were sourced from research study samples [[74](#_ENREF_74)]. When applying combined ADOS and ADI-R ratings mapped onto DSM-5 criteria, and including additional information from ADI-R items on repetitive behaviours, 93% of patients met DSM-5 criteria for ASD (specificity was not reported). These findings are of particular note given concerns about the ability of DSM-5 to identify ASD in higher functioning people raised by some earlier studies.

The implications of these studies for estimates of prevalence of ASD after the introduction of DSM-5 criteria is considered in **Section 2.3**.

Relaxing the algorithm

In view of concerns about reduced sensitivity from early studies of DSM-5’s accuracy, suggestions have been made to “relax the algorithm” for determining a diagnosis of ASD. For example, reducing the number of criteria needed to be met from the social communication and interaction domain from all three to two, and from the restrictive and repetitive behaviour domain from two to one (of 4) [[60](#_ENREF_60)]. It has been argued that relaxing the algorithm may particularly benefit assessment approaches which rely heavily on care-giver reports of early-life ASD symptoms [[53](#_ENREF_53)].

Many of the studies already described which investigated accuracy of DSM-5 criteria also explored the impact of relaxing DSM-5 criteria by one symptom on rates of ASD diagnoses. All studies found that sensitivity could be significantly increased with minimal loss of specificity [[31](#_ENREF_31), [53](#_ENREF_53), [57](#_ENREF_57), [69](#_ENREF_69), [70](#_ENREF_70), [73](#_ENREF_73), [83-85](#_ENREF_83)]. For example, by requiring one less symptom criterion, Frazier and colleagues [[53](#_ENREF_53)] increased DSM-5 sensitivity (from 0.81 to 0.93), with minimal reduction in specificity (from 0.97 to 0.95). It has been suggested that such an adjustment might be important to consider for those people whose early life symptoms are not easily obtained or accurately recalled [[60](#_ENREF_60)].

More recently, a study designed, tested and compared a set of ASD algorithms in two independent samples of adults [[86](#_ENREF_86)] using a different approach. Rather than relaxing the algorithms in terms of the number of criteria met in each of the two domains, the study altered the number of assessment tool items required for each DSM-5 subdomain. The assessment tool used was the Diagnostic Interview for Social and Communication Disorders (DISCO) which has been designed to identify autism spectrum disorders. The algorithm proposed in the DSM-5 (one item per subdomain) was compared with two alternative algorithms determined by statistical approaches (Receiver Operating Characteristic curves were used to identify the optimal threshold for each subdomain). Sensitivity was assessed across age and ability levels in an additional third dataset of individuals with an ICD-10 PDD diagnosis. Sensitivity was highest for the diagnostic algorithm adhering to the DSM-5 criteria, with acceptable specificity, with diagnostic performance maintained across age and ability levels.

2.3 Impact on prevalence

Impact on numbers diagnosed

There have been concerns that the DSM-5 criteria may be tighter and more stringent than under DSM-IV, such that some individuals who qualified for PDD (excluding Rett’s Disorder) will not meet the new criteria for ASD. The APA’s main objective of the revision to the DSM relating to ASD was to increase the specificity of diagnosis [[40](#_ENREF_40)]. The related APA fact sheet stated that the “Work Group believes a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed” [[81](#_ENREF_81)].

On face value, application of DSM-5 should not exclude most individuals with current DSM-IV diagnoses. While the domains in DSM-5 decrease from three to two, the proposed criteria encompass all symptoms currently included in DSM-IV except for language delay (which can be included as a clinical specifier). In addition, the proposed DSM-5 criteria expand the opportunity for diagnosis, including the addition of sensory sensitivities to repetitive, ritualistic behaviour, providing examples from different age ranges and severity levels, and the change of symptom onset in early childhood rather than prior to three years of age [[87](#_ENREF_87)].

There have been over a dozen studies investigating diagnosis under DSM-IV compared with DSM-5 manuals over the last few years, with widely varying estimates of the accuracy of diagnosis under the revised criteria. A series of studies considering the initial [[68](#_ENREF_68), [69](#_ENREF_69)] and revised draft DSM-5 criteria for ASD [[25](#_ENREF_25), [31](#_ENREF_31), [53](#_ENREF_53), [57](#_ENREF_57), [71-73](#_ENREF_71), [84](#_ENREF_84)] found increased specificity but decreased sensitivity of DSM-5 draft criteria compared to DSM-IV. Estimates ranged from a sensitivity of 46% found in a Finnish study including 26 children with ASD [[69](#_ENREF_69)] to 81% in a large study of siblings in families affected by ASD [[53](#_ENREF_53)]. In addition, 95% of 64 children included in the DSM-5 field trials retained their diagnosis of ASD under DSM-5 compared with DSM-IV diagnoses previously held.

Concerns have been raised that the methodology used in these studies may not be appropriate to fully assess DSM-5 criteria, suffering from a range of limitations. Key ones include:

* Studies have tended to access datasets from convenience samples (often, small) sourced from specialist or academic centres which tend not to be representative of broader populations typically referred for ASD assessment. Diagnostic accuracy can be exaggerated by selecting “case subjects” (from speciality clinics) who are unequivocally symptomatic and “control subjects” who are unequivocally asymptomatic, omitting the ambiguous middle of the population for whom diagnostic errors are the most common and most costly [[62](#_ENREF_62)].
* Studies have employed retrospective review of archival data and symptom counts based on DSM-IV criteria for autism as the reference test for establishing test accuracy, essentially considering the previous version of the manual as the reference standard against which DSM-5 criteria should be compared.
* Assessment of DSM-5 has tended to rely on data collected by instruments assessing DSM-IV criteria and then mapping these to DSM-5 criteria using an algorithm approximating the concepts in a limited and unblinded fashion (that is, whilst being aware of the diagnosis under the DSM-IV). Diagnostic instruments such as the ADOS and ADI-R were developed to align with the DSM-IV and therefore are more likely to have a better fit with the earlier version of the manual than the DSM-5. Further, these tools and symptom checklists do not contain all the items needed to assess DSM-5 (such as sensory sensitivities).
* Studies, particularly earlier ones, have used outdated, draft versions of proposed DSM-5 criteria where extra text and examples were not provided. Most studies also failed to consider the number of people failing to meet DSM-5 criteria for ASD who may now qualify for the new diagnosis of “social communication disorder [[51](#_ENREF_51)].

Uniquely, an exploratory prospective Australian study by Gibbs et al [[70](#_ENREF_70)] involved the same clinician using the same clinical information to record diagnosis firstly under DSM-IV criteria and then under DSM-5 criteria. In the small clinical sample of 132 children, the study found that 77% of those diagnosed with ASD under DSM-IV retained their diagnosis under DSM-5 criteria.

Huerta and colleagues conducted a very large study including more than 5000 children and adolescents aged 2 to 17 years identified retrospectively using data from three existing datasets and using best-estimate clinical diagnosis as the reference standard. When only parent-rated symptoms were used, they found few differences between the two systems in sensitivity, with a sensitivity of 91% for DSM-5 criteria compared with the previous system [[6](#_ENREF_6)]. Specificity was relatively poor for DSM-5 (Sp=0.53) but superior to DSM-IV (0.24-0.53 depending on diagnosis), and improved when using combined ADI-R and ADOS (Sp=0.63).

These studies all show that diagnosis under DSM-5 provides better specificity (thus reducing false-positive diagnoses) than under DSM-IV, but at the expense of somewhat reduced sensitivity, especially for older children, adolescents and adults, individuals without intellectual disability, and individuals who previously met criteria for diagnoses of DSM-IV Asperger's Disorder or PDD-NOS [[88](#_ENREF_88)].

In an attempt to clarify these issues, a recent study identified around 500 verbally fluent, high functioning people aged 5-61 with DSM-IV defined ASD from research study samples [[74](#_ENREF_74)]. Similar to Huerta et al’s study of children and adolescents, sensitivity was high, with 93% of patients meeting DSM-5 criteria for ASD. These findings are reassuring given concerns raised by some earlier studies about the ability of DSM-5 to identify ASD in higher functioning people.

On the basis of current evidence it is difficult to know precisely what impact DSM-5 will have on prevalence rates for ASD in real-life non-research settings, but this will become clearer as prospective, representively-sampled studies using appropriate assessment tools are completed [[51](#_ENREF_51)]. The question remains about how many individuals previously meeting criteria for ASD under DSM-IV may now meet criteria for the newly created Social (Pragmatic) Communication Disorder [[33](#_ENREF_33), [52](#_ENREF_52), [57](#_ENREF_57), [66](#_ENREF_66)]. The few studies to date which have considered this suggest that this may be a relatively small proportion [[4](#_ENREF_4), [6](#_ENREF_6), [57](#_ENREF_57), [75](#_ENREF_75)], however validated tools have not yet been developed for assessing SCD.

It can be argued that there should be no specific expectations about changes in the prevalence of disorders in DSM-5 compared with the prevalence for the corresponding DSM-IV diagnoses. To require that the prevalence remain unchanged is to require that any existing difference between true and DSM-IV prevalence be reproduced in DSM-5. Any effort to improve the sensitivity of DSM criteria will result in higher prevalence rates, and any effort to improve the specificity of DSM criteria will result in lower prevalence rates [[62](#_ENREF_62)]. The use of arguably more stringent and reliable diagnostic criteria may allow for improved confidence in prevalence information in the future [[38](#_ENREF_38)].

People who already have an established diagnosis

There have been widespread reports of family anxiety about the removal of subtypes such as Asperger syndrome and the possible need for re-diagnosis. The diagnosis of ASD can be a particularly difficult process to come by with long waits, challenging systems and a series of formal evaluative steps required. Understandably, some families are concerned about the idea of revisiting or reopening the diagnostic process [[27](#_ENREF_27)].

The (US) Autism Society has strongly advocated for people with ASD maintaining access to existing services and waiting list positions [[3](#_ENREF_3)]. Concern about the impact on special education programmes for those already diagnosed with ASD who may no longer fill the DSM-5 criteria led to the addition of a note (see **Appendix** **A4.1**) in the manual under the description of the diagnostic criteria:

Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder.

This addition has been criticised as a “bizarre twist from the perspective of diagnostic logic” by “grandfathering in” people currently being treated regardless of whether they satisfy the current criteria [[89](#_ENREF_89)]. This approach nevertheless conforms to earlier calls prior to the DSM-5’s publication that the diagnostic criteria be used prospectively and that people not be formally rediagnosed unless there is some clinical reason to do so [[27](#_ENREF_27)]. In such cases it could be explained to individuals and their families that “the field has moved toward thinking of the ASD difficulties along a continuum within which distinct diagnostic boundaries that persist over time do not clearly exist” [[43](#_ENREF_43)].

Whilst the DSM-5 impacts on the clinical diagnosis, it is important to recognise the value of a diagnosis within a cultural, social and service context. This particularly applies to Asperger syndrome, where the term may continue to be used in society as an identifying label regardless of whether it is retained as a clinical diagnosis. This is discussed in the next section.

2.4 Cultural implications

Since the announcement in February 2010 of proposals to remove PDD subtypes such as Asperger syndrome as distinct disorders in the DSM-5, there has been extensive discussion among stakeholders, including clinicians, scientists, advocacy groups, and policy makers, but particularly among those most likely to be affected, people with diagnosis of/self-identifying with Asperger syndrome [[90](#_ENREF_90)].

Neurodiversity

The term ‘neurodiversity’ was coined in the late 1990s for the (already existing) concept whereby members of the autistic community, together with self-advocates representing other developmental conditions such as ADD (attention deficit disorder) and dyslexia, promoted and celebrated their difference from ‘neurotypical’ peers as a positive identity, not necessarily a disability [90,91].

The concept of neurodiversity considers atypical neurological development to be normal human difference that should be accepted and respected, just as other differences such as those defined by class, gender or race are (or should be). From this perspective, autism is considered not something to be cured, but rather a way of being with both disadvantages needing accommodation, and advantages that can make a unique and positive contribution to society.

Since the addition of the Asperger syndrome diagnosis in DSM-IV [[15](#_ENREF_15)], a distinct subculture has emerged of people with Asperger syndrome (some of whom self-refer as “Aspies”) who embrace their neurological difference [[90](#_ENREF_90)].

It has been suggested that this independent culture relies upon a restrictive view of high-functioning autism as being distinct from others on the spectrum. And so, whilst autism conditions associated with lower functioning may be considered disorders requiring treatment, the higher functioning characteristics of Asperger syndrome should not be pathologised as a disorder and subsumed under the category of autism spectrum disorder in the DSM [92]. Conversely, some in the autistic community have an abhorrence of being classified as either ‘high functioning’ or ‘low functioning’ [91, 93]. Rather, those diagnosed or self-identifying anywhere on the spectrum are welcomed and accommodated [93].

Identity

For many people with Asperger syndrome, as with autism disorder more broadly,the diagnosis has come after years of anxiety and confusion and represents a turning point in their lives [94]. Frequently, individuals who are diagnosed in adolescence or adulthood report that receiving a diagnosis results in a conceptual framework that helps explain past experiences, creates greater self-understanding and leads to informal support and an awareness of additional service options [95]. Disclosing the diagnosis can have pitfalls however, and is best approached with care [94].

For people who do not seek a formal diagnosis, the desire to self-identify as having Asperger syndrome/ASD and to join the AS (or ASD) community, may be driven by the understanding, acceptance and support that such a community can offer.

Alongside the growing professional recognition and debate around Asperger syndrome before and since its inclusion in the DSM-IV [[15](#_ENREF_15)], awareness of Asperger syndrome (and autism more generally) is becoming part of mainstream culture, facilitated by public awareness initiatives, and fictional media portrayals over the past decade (e.g., Sheldon in *The Big Bang Theory*, and the title characters in *House*, and *Monk)* [96]. Linking autism to famous intellectuals and innovative thinkers contributes to a view of people with AS as a group of highly intelligent, highly successful individuals making positive contributions to society. Embracing these positive images have been people who are diagnosed, self-diagnosed, or associate themselves with AS, who have developed a positive identity of Asperger syndrome beyond the diagnostic boundaries [[90](#_ENREF_90)].

However an extreme emphasis on positives also has negative ramifications, such as instances of sub-cultures promoting ‘Aspie supremacy’ that cause other individuals with autism (including many with AS) further isolation, disadvantage, and/or stigma[97, 98].

A study including interviews with 19 adults with Asperger syndrome and analysed using grounded theory illustrates how the diagnosis and self-diagnosis of AS is fused with a strong and positive individual identity [[90](#_ENREF_90)]. For some diagnosed with Asperger syndrome, being labeled “autistic” and associated with people at the “lower end of the autism spectrum” is problematic and potentially stigmatising [[11](#_ENREF_11), [90](#_ENREF_90)]. The negative stereotypes placed on autism may stem from a lack of understanding among the general public of the variability in symptoms among people on the autism spectrum. Jaarsma & Welin [92] suggest that those with Asperger syndrome who are able to live independent lives in the right environment may find the notion of their condition being combined with lower functioning autism in DSM-5 an “even worse stigmatisation” [92]. It is suggested that instead of being labelled using “deficit-based language,” such people should be considered as having a “particular *vulnerability”*.

Tony Attwood, a psychologist specialising in working with people with Asperger syndrome, believes the new criteria may create further social confusion.

*“The problem is not the condition but the attitude of other people. When you're young, self-esteem is created within a peer group, not from mum or dad. Teenagers may worry that their peers have an idea of autism. The public see autism as a severe disability. People may think the person is lying or deluded if they say they're autistic” [96].*

It has been hypothesised that under the new DSM-5 criteria, a perceived stigma attached to autism may inhibit disclosure and self-identification with Asperger syndrome, and as a result cut off attendant benefits of diagnosis including the development of meaningful self-identities and gaining legitimacy. Such “stigma by association” stems from negative stereotypes placed on autism and lack of understanding by the general public about the variability in symptoms among people on the autism spectrum [[90](#_ENREF_90)]. Dispelling stigma around autism, ensuring balanced information upon diagnosis, and providing well-informed support around disclosure are likely to assist in addressing issues around identity for those on the spectrum. The ASD Guideline [1] includes a recommendation (7.4) relating to stigma: “An ASD antidiscrimination and destigmatisation campaign should be developed”.

Bringing Asperger syndrome into ASD

Discussions about the potential loss of identity from the removal of PDD’s from DSM-5 tend to focus on the removal of Asperger syndrome, rather than PDD-NOS and childhood disintegrative disorder, which appear to have a less distinct culture. It could be argued that including Asperger syndrome in the diagnostic classification of autism spectrum may increase the recognition of the breadth and variability of the condition. And so, over time, the stigma attached to the label of autism would be reduced as the positive associations with Asperger syndrome become associated with the broader condition of ASD.

Inclusion may also be advantageous to many people with Asperger syndrome who feel that the challenges they face socially are underestimated, and who already choose to identify as “autistic” for these and other reasons [eg; 91, 93, 97, 98]. The emerging positive image of Asperger syndrome in society can be a double-edged sword, as illustrated by the comment from this parent of a child with Asperger syndrome:

“In fact, as soon as you say Asperger's, people immediately think: gifted, superior, savant. That's why I always use the term high-functioning autism to describe Darcy: to minimise any unrealistic expectations of him.” [99]

However, whilst not wanting neurological difference to be medicalised and treated as a disorder, people anywhere on the autism spectrum may still require special care, provisions, allowances and support. People identifying as having Asperger syndrome with or without an official diagnosis, discuss facing everyday challenges of communication, social interaction, and misunderstanding. They talk of struggles leading to social isolation and feeling misunderstood, and feelings of anxiety, guilt, and a sense of shame. Such challenges are expected to persist despite the changes in nomenclature in the DSM-5 [[90](#_ENREF_90)]. For such people who do not seek a formal diagnosis, the desire to self-identify as having Asperger syndrome may be driven by the understanding, acceptance and support that belonging to such a community can offer.

An advantage of the DSM-5’s emphasis on individualised assessment in severity ratings supplemented by personal strength-based characteristics is that it can direct needs-based support. People who are functioning well and require no formal intervention for (some) aspects of their functioning can have this recorded through associated severity ratings, or in some cases where no support is needed, seek no formal diagnosis. Such people will continue to have the option to seek identity, peer support and understanding from either the ASD community (made up as it always has been of individuals right across the spectrum) or any “Aspie” or other sub-culture. This choice also takes the definition (and control) of the word Asperger out of the domain of a deficit-based classification system of “mental illnesses” and into the hands of those who choose to name and claim their own moniker.

Several autism organisations have been cautiously positive about the DSM-5 changes [87, 100-102]. The National Autistic Society (UK) welcomes the overall approach, stating that the diagnostic criteria are helpful, clearer and simpler than the previous DSM-IV criteria, and approve the development of dimensional measures of severity, inclusion of sensory behaviours, and the emphasis on identifying the full range of difficulties that an individual has. With respect to Asperger syndrome, they note that diagnosticians might still use the term colloquially, refering to a person as having “ASD of the Asperger’s type”, adding that many people who identify closely with the term Asperger syndrome will continue to use it in everyday language [[6](#_ENREF_6)]. The Asperger’s Society of Ontario suggest that it may make it easier for people to understand what Asperger syndrome is by folding it into the ASD banner, noting “when asked to describe Asperger syndrome, most explain it as a higher functioning form of autism” [100].

It is not clear what impact the changes in the DSM-5 will have in New Zealand or internationally. However there is no reason that self-advocates, families, and advocacy organisations cannot continue to use the term Asperger syndrome or that people may not benefit from joining groups that define themselves in terms of previous definitions [[35](#_ENREF_35)]. Medical diagnoses are not intended to define a person or capture the complexity of an individual’s cultural identity and unique personal history [[38](#_ENREF_38)]. Even though the formal diagnosis may be Autism Spectrum Disorder, individuals who are familiar with the Asperger syndrome diagnosis can make reference to it on their medical files [100]. This is already the case for people with High Functioning Autism (HFA), which is not a formal clinical diagnosis but is a term used by clinicians and affected individuals to assist in understanding and describing their condition. As the various terms, Aspies, Autists, Aspiens, Aspers,Auties and Aspergians continue to carry meaning and value for a self-selecting community they are likely to continue to be used.

And so just as a broader, richer autistic community and culture have developed independently from and beyond a manualised classification of autistic conditions, terms such as Asperger and ‘Aspie’ may continue to have life as identities as distinct from a diagnostic classification.

2.5 Clinical implications

Clinical utility

Practical issues relating to the implementation and use of the new DSM-5 criteria clinically have been considered. It has been suggested that with a single diagnostic classification of ASD, fewer clinical resources will be needed (without the requirement to distinguish between related autistic subtypes) which may lead to a quicker and more stable diagnosis [[3](#_ENREF_3), [38](#_ENREF_38)]. A diagnosis of ASD may also be more flexible compared to a narrow categorical diagnosis, especially as people age and experience different symptoms and levels of severity over their lifespan [[90](#_ENREF_90)].

A criticism of the move to a single diagnostic entity is the loss of a sense of heterogeneity and diversity in the diagnosis and its treatment. Whether or not Asperger syndrome is distinct from autism, some clinicians have argued that the term has become clinically useful in identifying a set of individuals who respond to a different set of interventions than those with typical autism [103]. The increased awareness of Asperger syndrome as a distinct diagnosis in DSM-IV is likely to have contributed to a creation of specialist services for milder forms of autism less prominent previously.

Countering this argument, it has been suggested that services and treatment strategies are best when needs-based, planned around an individual’s strengths and weaknesses rather than their diagnostic label [[38](#_ENREF_38)]. A range of services will therefore continue to be needed to reflect individual variation in severity of symptoms and other clinical characteristics under diagnosis using DSM-5. To this end, the additional requirement of symptom severity levels and clinical descriptors can help individualise a diagnosis, and provide more personal information about a person’s abilities and challenges. And so, instead of a diagnosis of Asperger syndrome, under DSM-5 criteria a person may receive one of “ASD with good language skills and high intelligence, requiring support for his social communication and requiring very substantial support for his repetitive behaviour” [[38](#_ENREF_38)].

Further, it has been suggested that combining social and communication domains into one under DSM-5 may move diagnostic attention from when and to what extent language is developed, to how a person communicates and initiates social interactions. Such a focus has been hypothesised to lead to earlier diagnoses for those children who do not have delayed language who are typically diagnosed later under DSM-IV criteria [[38](#_ENREF_38)].

The addition of the new category of Social Communication Disorder (SCD) within the DSM-5 may lead to diagnostic changes that are not currently predictable [103]. There has been significant disagreement among researchers about the utility of the newly defined disorder of SCD [[35](#_ENREF_35)]. There is little data on its reliability, validity or prevalence and questions remain about whether this condition is different from ASD in aetiology, symptom profile management, or prognosis [[33](#_ENREF_33), [40](#_ENREF_40)]. There are concerns that, like PDD-NOS in DSM-IV-TR, SCD will become a loosely defined residual diagnosis vulnerable to the same problems encountered with PDD-NOS [[52](#_ENREF_52)]. Assessment and treatment protocols will need to be developed to provide direction for support for this newly defined group of people, some of whom would have fulfilled criteria for PDD/ASD under DSM-IV-TR.

The UK’s National Autistic Society [[7](#_ENREF_7)] suggest from their assessments that people with social communication disorder usually do have restricted or repetitive behaviours and interests, but have been able to mask them, particularly where someone is more able intellectually. They conclude that SCD is a subgroup of ASD and that it has not been helpful to have created it as an additional diagnosis outside ASD. This perspective is opposed by Susan Swedo, the Chair of the work group responsible for updating DSM criteria for ASD, who argues that SCD and ASD should be completely separate diagnoses. In a meeting with the Interagency Autism Coordinating Committee about implementing the DSM-5 criteria, Swedo states that:

“the data available to date show that individuals, who otherwise meet criteria for ASD in the broadest diagnostic sense, but who do not exhibit repetitive behaviors/restricted interests at the present, do have an early childhood history of these behaviors” [[75](#_ENREF_75)]

And so where such behaviours have been masked or overcome in adulthood, but were present in early childhood, a diagnosis of ASD should be applied, not SCD. Swedo acknowledges that this might pose some methodological limitations for assigning diagnoses based on school records because these only document current symptomology. Other reasons for lacking evidence of early history include where early memories are scant or where there are no family members or early records to provide details of early childhood.

Clinical feasibility and acceptability

Some empirical work has been conducted relating to the reception of the new criteria by clinical professionals.

Prior to its release, many service providers had concerns about the DSM-5 with respect to its diagnostic changes for autism. In an Australian study of 547 health and education professionals, half of the participants reported being opposed to (draft) diagnostic changes, 22% supported the proposed changes, and 28% expressed uncertainty [105]. The most common reason given for professionals being against the changes related to a view that autism and Asperger syndrome are different conditions, with different characteristics and intervention needs. Whereas those supporting the changes tended to argue that these conditions were within the same spectrum. Some educationalists suggested that greater service access may be possible for people with Asperger syndrome being brought under a broader autism classification.

As part of their DSM-5 field trials, the APA evaluated clinical utility and feasibility of proposed DSM-5 criteria in routine clinical practice (RCP) settings [5], as contrasted with the high volume academic and research centres used in previous field trials evaluating reliability [[4](#_ENREF_4), [63](#_ENREF_63), [64](#_ENREF_64)]. The data were collected online for six months from October 2011 from a wide range of practice settings in the US, Canada, Australia and the UK. Clinicians from various disciplines were recruited from two sources, a random sample of 9,460 psychiatrists in the US and a volunteer (essentially, convenience) sample of 5,600 mental health clinicians recruited primarily through the DSM-5 website.

Participating clinicians received staged, online training to conduct diagnostic interviews, and completed DSM-5 and related assessments. Consecutively recruited patients aged over six years completed self-assessments of cross-cutting symptom domains and disability measures which were provided to their clinician prior to their diagnostic interview. Clinicians and patients (or their caregivers) were also given questionnaires to evaluate the utility of these tools.

A total of 621 clinicians provided data for 1,269 patients (164 aged 6-17, 1105 aged 18 years or over). Only 22 patients (2% of the whole sample) were diagnosed with ASD as their primary diagnosis, precluding sub-analyses for that group (co-occuring diagnoses were not addressed). For the whole sample, about half of clinicians reported that the DSM-5 approach was very or extremely easy for assessment of pediatric (51%) and adult (46%) patients and very or extremely useful in routine clinical practice for pediatric (48%) and adult (46%) patients. Most (85%) clinicians considered the DSM-5 approach to be better (57%) or much better (18%) than that of DSM-IV. Patients/caregivers (47-72% depending on age-range) also reported that the DSM-5’s cross-cutting measures would help their clinicians better understand their symptoms.

It was acknowledged that the study was limited by a relatively low response rate by clinicians who were likely to be highly motivated and self-selected rather than a representative sample. The authors concluded that the DSM-5 approach was feasible and clinically useful in a wide range of routine practice settings and favourably received by both clinicians and patients.

2.6 Impact on services

Some of the revisions to ASD criteria in the DSM-5 have been broadly welcomed as moving toward the provision of integrated services across the spectrum. With the additional information in diagnosis provided by clinical specifiers, severity ratings and cross-cutting dimensional measures, needs-based services can be tailored to the individual with respect to sociability, language disorder, sensory responsiveness, intelligence, and comorbid conditions, rather than with just a diagnostic label [106].

In some quarters, concerns have been raised about the possible impact on treatment planning, prognosis information, and eligibility for services of removal of AS, CDD and PDD-NOS as distinct diagnoses with ASD [107, 12]. This may particularly be the case for commercial insurance companies which depend on clinical diagnosis for reimbursement for specific services [107].

Elsewhere, it has been suggested that the removal of diagnostic distinctions between PDD subtypes may increase equity across the autism spectrum with respect to treatments covered by third party payers [[35](#_ENREF_35)] and access to educational services and targeted treatment [[90](#_ENREF_90)]. In some countries, individuals with Aspergers syndrome and PDD-NOS have not previously qualified for government-funded autism services but now may become eligible under DSM-5 [[3](#_ENREF_3), [33](#_ENREF_33)]. There is hope among some autism organisations that greater awareness will mean that those with Asperger syndrome, who previously never had access to services because they were less visible, will now receive the supports and services they need [100].

In the US, there are some disparities in services offered to affected individuals by diagnosis. A diagnosis of autism is eligible for speech, occupational, physical, and behavioral therapies, whereas funding for other diagnoses within the Neurodevelopmental Disorders category is significantly less [[12](#_ENREF_12)]. The ability to be diagnosed with comorbidities in addition to ASD and the the additional information provided by clinical descriptors under DSM-5 may also ease access to assistance for problems commonly associated with the autism spectrum, including ADHD, learning and coordination disorders and anxiety disorders.

Some have criticised the idea of maintaining the existing, broad autism spectrum, stating that doing so takes limited resources away from those most in need. Refuting this argument, a joint statement of the Autism Self Advocacy Network (ASAN) and Autism Society on DSM-5 [95] observes the following:

“No publicly funded resource is accessible to autistic adults and children solely on the basis of a diagnosis. Furthermore, while the fact that an individual has a diagnosis of autism spectrum disorder does not in and of itself provide access to any type of service-provision or funding, a diagnosis can be a useful contributing factor in assisting those who meet other functional eligibility criteria in accessing necessary supports, reasonable accommodations and legal protections”.

The DSM-5 is a clinical manual and impact on service eligibility is yet to be determined. Special education determinations do not necessarily follow clinical diagnoses [[51](#_ENREF_51)]. Possibilities surmised (but not foreshadowed) include that funding may be tied to the severity ratings applied to the diagnosis under DSM-5 such that patients requiring “very substantial support” will receive greater access to services than those with “mild ASD” [[38](#_ENREF_38)]. However, whilst it is understood that severity levels may vary by context and also fluctuate over time, the APA’s intention is that they should not be used to determine eligibility for and provision of services [[7](#_ENREF_7)].

Chair of the work group responsible for the DSM-5’s changes with respect to ASD, Dr Susan Swedo, has said that the work group intended the severity ratings to be specifiers, not subtypes. They were designed specifically to denote the severity of ASD in each of the individual domains rather than for ASD overall. Swedo adds that this was done purposely to make it more difficult for anyone to misuse the three levels and to classify people with ASD into high- and low- functioning or other broad categories that may be misleading, as many in the autistic community have observed (see Section 2.4).

And so:

“The severity levels 1, 2, and 3 do not translate to "mild", "moderate", and "severe"; these should not be used as treatment targets or a reason for denying services to individuals… the levels are intended to help clinicians get a sense of an individual's impairments” [[75](#_ENREF_75)]

It is currently unclear how people diagnosed with the newly defined, non-ASD diagnosis of social communication disorder will fare in the service environment [[31](#_ENREF_31)]. It is not known whether they will become eligible for speech therapy, and whether speech-language therapists will have the capacity and training to case manage the influx of new patients [[3](#_ENREF_3)]. It is also not clear whether people diagnosed with SCD will be eligible for interventions available to people with ASD.

2.7 Research implications

Lumpers versus splitters

In contrast to the categorical approach of classification of disorders under DSM-IV, DSM-5 uses a combination of category and dimensional diagnoses, combining subtypes to form one ASD condition expressed at different levels of severity.

It has been argued that the DSM-5 approach compared with the DSM-IV approach can be summarised as “lumpers” (of subtypes into a single disorder) versus “splitters” (of ASD into distinct disorders), with benefits and limitations to both approaches [109]. Some have suggested that DSM-5’s approach of “lumping” together factors that may have unique biological substrates may limit investigation of the aetiology of ASD [88, 109, 110]. Others have argued that considering an overarching single condition of ASD has scientific utility in reflecting the genetic and neurobiological similarities between individuals on the autism spectrum [[90](#_ENREF_90)]. Researching ASD as a single condition may therefore help detect any common aetiologies, endophenotypes, and genetic markers [[60](#_ENREF_60)]. Further, if distinct sub-groups can be reliably identified and it makes clinical sense to distinguish them, the DSM-5 can be updated accordingly [111, 112].

The National Institute of Mental Health (NIMH) has launched the Research Domain Criteria (RdoC) a 10-year effort to define mental disorders based on behavioral and brain measures. The project attempts to identify both biological and symptomatic dimensional measures of psychopathology that correlate with genetic, neuroimaging, and neuropsychological factors irrespective of current diagnostic boundaries [113]. In a blog by NIMH Director Thomas Insel, the DSM-5 was initially criticised for its “lack of validity”, with Insel declaring that NIMH will be “re-orienting its research away from DSM categories” [[29](#_ENREF_29)]. In a more conciliatory joint press release a fortnight later, Insel and APA’s President-Elect Jeffery Lieberman stated that DSM-5 and RDoC represent complementary, not competing, frameworks on the path to better diagnoses for mental disorders. Furthermore the statement observed that “as research findings begin to emerge from the RDoC effort, these findings may be incorporated into future DSM revisions and clinical practice guidelines” [114].

A different slant on this debate is the suggestion that researchers move away from investigating aetiology and focus rather on the behavioural manifestations of ASD, which may provide opportunities for developing supports targeting these behaviors [104]. The movement toward introducing cross-cutting measures of shared symptoms across disorders in DSM-5 is consistent with this approach.

Ongoing research studies

Major changes in diagnostic practice complicate interpretation of earlier research, potentially compromising generalisation of results [115]. There is also the potential for disruption of ongoing longitudinal, clinical and biomedical studies which enrolled patients using DSM-IV diagnostic criteria [[24](#_ENREF_24)].

To get around some of the difficulties of comparability across diagnostic systems, it has been suggested that a parallel record of DSM-IV diagnoses be maintained, and PDD diagnoses (excluding Rett’s disorder) be regarded as equivalent to ASD [[32](#_ENREF_32), [88](#_ENREF_88)]. Alternatively, severity data and additional clinical information available from the more rigorous studies could be used to re-assign DSM-IV diagnoses under DSM-5 criteria [[38](#_ENREF_38)], although the pitfalls of retrospective diagnoses using archival data have already been discussed above.

Accessibility for marginalised groups

Particular effort is needed to ensure that the criteria for ASD in the DSM-5 are culturally competent and accessible to under-represented groups. In a joint statement of the Autism Self Advocacy Network (ASAN) and Autism Society regarding the DSM-5 [95], it is observed that racial and ethnic minorities, women and girls, adults and individuals from rural and low-income communities have faced challenges in accessing diagnosis, even where they clearly fit criteria under the DSM-IV. A criticism of the first DSM-5 field trial was that it was limited to school-age children of primarily Caucasian background and evaluated by specialists in academic centers [101].

Responding to these gaps in knowledge a study in South Carolina, funded jointly by the Centers of Disease Control and Prevention and Autism Speaks, is underway comparing the DSM-IV and DSM-5 criteria in a large, ethnically diverse, community-based sample of children [116]. This is in addition to [another community study](http://www.autismspeaks.org/science/grants/asd-prevalence-dsm-iv-and-dsm-5-total-population-study?destination=about-us%2Fgrant-search%2Fresults%2Ftaxonomy%3A9771+DSM-5) comparing diagnoses under the two sets of criteria in children in South Korea [117].

In addition to these evaluations, materials will need to be developed for assisting diagnosis in primary care settings, in culturally diverse populations and for non-English-speakers [[4](#_ENREF_4), [32](#_ENREF_32), [74](#_ENREF_74)]. Evaluation and validation of the Cultural Formulation Interviews offered as emerging measures in the DSM is required. These schedules, including separate versions designed for completion by clinicians and by caregivers as well as more in-depth supplementary modules for considering culture for specific groups, aim to assess the impact of culture on key aspects of an individual’s clinical presentation and care (see **Appendix 5**).

Assessment tools

Current “gold standard” assessment tools for research include the clinician-rated Autism Diagnostic Observation Schedule (ADOS) and the caregiver-reported Autism Diagnostic Interview, Revised (ADI-R) which were originally developed to align with the DSM-IV-TR. DSM-5 criteria for ASD are not precisely mapped to these tools and will need to be modified to assist researchers and clinicians in diagnosing ASD according to the new criteria as accurately as possible.

There is a need for the development of diagnostic instruments that will capture historical information regarding repetitive behaviors in early childhood, as this is now an essential component of accurate diagnosis [[75](#_ENREF_75)]. The most commonly used research measures, the ADOS and the ADI-R, are not widely used by clinicians because of copyright protections, cost, complexity and administration time, particularly in primary care [[15](#_ENREF_15)]. The large trial of children by Huerta et al [[6](#_ENREF_6)] found that sensitivity was best using criteria based on ADI-R alone. Consistent with this, another study of high functioning children and adults reported that the ADOS is more limited than the ADI-R in capturing DSM-5 symptoms, particularly related to repetitive behaviours [[74](#_ENREF_74)]. Assessment instruments will need to be adapted or developed for use with the DSM-5 [[4](#_ENREF_4)], although assessment by an expert clinician is likely to remain the “gold standard” of diagnosis [[75](#_ENREF_75)].

Research directions

* Some of the more dramatic changes in criteria used in DSM-5 are likely to require further development and lead to new avenues of research.
* The inclusion of sensory abnormalities as a core, diagnostic symptom of the restricted, repetitive patterns of behaviour domain may stimulate research interest in the features and causes of abnormal sensory processing in ASD [[55](#_ENREF_55)].
* Strategies are needed to improve the ability to make a diagnosis of ASD in the absence of reports of early history [[51](#_ENREF_51)], particularly for older children and adults seeking diagnosis.
* A thorough evaluation of the revision with respect to the new diagnostic category of Social (Pragmatic) Communication Disorder requires research attention [[88](#_ENREF_88)]. There is currently a lack of field data and guidance on service implications for SCD [[40](#_ENREF_40)]. Suitable instruments are keenly needed to measure social communication skills and determine distribution in the population, assign cutoff points, operationalise mild and moderate impairment, and measure adaptive functio [118].

DSM as a living document

DSM-5 is intended to be readily updatable as a “living document”. The goal is that the manual be revised online with subsequent versions labeled DSM-5.1, 5.2 etc, so as to incorporate new evidence more quickly. As scientific data emerges and practical and social issues debated in the community, there will be amendments, clarifications and revisions over the course of the new edition's lifespan. Processes will need to be developed for documenting the evidence base for revisions in the DSM-5 electronic archives [[4](#_ENREF_4)].

2.8 Conclusions

This review updates evidence for the New Zealand Autism Spectrum Disorder Guideline [[1](#_ENREF_1)] with respect to the diagnostic classification of ASD in view of the latest version of the Diagnostic and Statistical Manual of Mental Disorders, the DSM-5 [[2](#_ENREF_2)]. Following a comprehensive database search and reference checking of research published since 2004, 123 articles were retrieved as full text, and 93 were found to be directly relevant to the review scope. In addition, the dedicated DSM-5 website and those of prominent autism advocacy, research and support organisations were searched for position statements and featured commentaries. These provide additional background and context to the controversial changes to the classification of ASD and their reception.

The literature considered for this review is substantial given the targeted nature of the search and the recency of publication of the DSM-5. It is likely that some articles pertinent to the broader issues relating to diagnosis of ASD have been missed.. However, given the extensive reference checking and website searching involved, it is likely that any key, influential studies missed in searching would have been subsequently identified.

Autism has been considered a spectrum condition for many years, as recognised in the New Zealand ASD Guideline [[1](#_ENREF_1)]. The rationale behind the revisions of the clinical manual is evidence-based, supported by a rigorous, transparent and consultative development process by an international team and extending over many years.

Preliminary indications of clinical utility are positive. In DSM-5 field trials [[4](#_ENREF_4)], inter-rater reliability appears to be good, although the sample for ASD diagnosis was small and requires verifying in broader populations. The criteria appear to be acceptable and feasible in trials in routine practice settings, at least for motivated participants following significant online training [5].

Whilst the DSM-5 criteria were publicly released only a matter of months ago at time of writing, considerable research has already been published relating to the diagnostic yield of the new ASD criteria compared with the previous version. Since 2011, fourteen such studies have been published representing a diverse range of samples and approaches. Comparing diagnosis under DSM-IV-TR criteria, studies suggest improved specificity for DSM-5 (leading to fewer people without ASD being mistakenly diagnosed with the condition) but somewhat reduced sensitivity, ranging widely from 46% to 95% (see **Table 2**). Interpretation is hampered by methodological differences and limitations, in particular, a reliance on existing datasets for determining DSM-IV diagnoses retrospectively from medical notes and symptom checklists. Also problematic are the imperfect attempts to assess the DSM-5 criteria by mapping them to responses to items designed to inform diagnosis under DSM-IV.

A large study of over 5000 children and young people using best estimate clinical diagnoses found that a high majority (91%) of people diagnosed with an ASD under DSM-IV-TR criteria (identified retrospectively) would retain a diagnosis of ASD when diagnosed according to DSM-5 criteria [[6](#_ENREF_6)]. Specificity was not high (0.53-0.63 depending on assessment strategies) but was improved over DSM-IV-TR. A recent study including high functioning, verbally fluent children and adults found a similarly high sensitivity (93%) [[74](#_ENREF_74)].

Whilst these results are reassuring, given the limitations of the studies conducted to date the true sensitivity and specificity of DSM-5 criteria for ASD remains unclear, as is the impact on prevalence of ASD. To best determine sensitivity and specificity of either diagnostic system, large, population-based prospective field trials are needed using an independent reference standard and concurrent assessment using the two systems, blinded to the comparison diagnosis. It is understood that two large, population-based trials are currently underway which aim to investigate prevalence under the two DSM versions more robustly [116, 117].

DSM criteria provide the foundation for the development of diagnostic tools, which require revision, development and validation in light of the DSM-5. However it is important to recognise that, ultimately, clinical judgement requires a global assessment of whether someone has symptoms which cause impairment to their everyday functioning.

Until high quality prospective trials are published, assessment tools are finalised and validated, and clinicians begin to apply the new criteria prospectively, many of the questions about clinical use and impact on prevalence of ASD remain uncertain. This is particularly the case for the new disorder of Social (Pragmatic) Communication Disorder. As DSM-5 is intended to be a living document, revisions are anticipated where justified by new research, though the process for this is currently unclear.

As DSM-5 is introduced there will need to be ongoing involvement of key stakeholders to ensure that individuals with ASD and families have strong voices as service systems grapple with potential changes in diagnostic classification [[58](#_ENREF_58)]. The APA states that those currently with a well-established diagnosis of Autistic Disorder, Asperger’s Disorder or PDD-NOS be given the diagnosis of Autism Spectrum Disorder. Regardless of the changes to the classification of ASD in what is fundamentally a diagnosticians’ clinical manual, individuals may choose to refer to themselves using their own terms of belonging to a culture that transcends diagnosis.

3 Implications of DSM-5 for ASD Guideline

This chapter reports the development of revised and new recommendations by the Living Guideline Group to supplement the ASD Guideline [[1](#_ENREF_1)] on reviewed evidence relating to DSM-5’s changes to diagnostic classification of ASD.

3.1 Response to the DSM-5 changes

The Living Guideline Group echos the UK’s National Autistic Society (NAS) [[7](#_ENREF_7)] in finding the DSM-5 revised diagnostic criteria helpful, being clearer and simpler than the previous DSM-IV criteria, and in welcoming the development of dimensional measures of severity, the inclusion of sensory behaviours, and the emphasis on identifying the full range of difficulties that an individual may experience as well as other relevant factors. The LGG also observe that whilst Asperger syndrome may no longer be a distinct diagnostic entity diagnosed under the DSM-5, the concept retains clinical utility in terms of family understanding, self identity, and as a tool for guiding educational and behavioural interventions and informing services and supports.

The Living Guideline Group recognise that people who identify closely with the term Asperger syndrome may continue to use it in everyday language. And so, regardless of the changes to the classification of ASD in what is fundamentally a diagnosticians’ clinical manual, individuals may choose to self-refer using their own terms of belonging to a culture that transcends psychiatric diagnosis.

How to read the ASD guideline in view of DSM-5

The NZ ASD Guideline (2008) [1] was prescient in recognising the movement toward considering autism as a spectrum condition and in the guideline’s title and frequently throughout the text and recommendations, the umbrella term of Autism Spectrum Disorder has been used. Nevertheless, when the original guideline was written the DSM-IV-TR manual was current and the terms Asperger syndrome and PDD-NOS were used in research. The Living Guideline Group advise that, in view of the DSM-5, where these terms are used in the guideline they should be read as refering to ASD.

3.2 Revision of guideline recommendations

The Living Guideline Group were tasked with considering the systematically updated evidence on changes to diagnostic classification of ASD in the DSM-5 reported above in terms of its implications for the ASD Guideline [[1](#_ENREF_1)]. Specifically, they considered whether the new evidence required revisions of (potentially relevant) existing recommendations as well as the development of any new recommendations. Both text of recommendations and their graded “strength of evidence” (see Appendix 1, **Table A1.2**) were considered at an all day face-to-face meeting in November 2013. The LGG’s decisions for recommendation development and grading are presented below. Revised or new recommendations are accompanied by a brief rationale which highlights any particular issues that the LGG took into account while formulating the recommendations.

Unchanged recommendations

One recommendations from the original ASD Guideline [[1](#_ENREF_1)] relevant to the current review update was considered as requiring no change in view of the updated evidence. This recommendation was:

* Recommendation 1.2.6. “Test users should ensure that they are aware of the validity, reliability and appropriateness of tests when assessing people with ASD and take these limitations into account when forming opinions and reporting results”. Grade C.

Rationale: Leave unchanged. Some diagnostic tools in use are based on DSM-IV criteria, however tools based on DSM-5 are currently in development. It remains the case that the reliability, validity and appropriateness of assessment tools need to be considered when assessing ASD.

Deleted recommendations

The following Good Practice Point in the ASD Guideline [[1](#_ENREF_1)] were deleted by the Living Guideline Group.

* Original Good Practice Point 1.3.5: “Diagnosis of ASD in itself may be sufficient. Attempts to delineate ASD from Asperger syndrome may not be valid and are not necessary.” GRADE **✔**

Rationale: This Good Practice Point was removed as considered redundant in view of DSM-5 criteria where DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.

Revised recommendations

Four recommendations in the ASD Guideline [[1](#_ENREF_1)] were revised by the Living Guideline Group. The final wording and grades for this recommendation is presented in **Table 3**.

* Original Recommendation 1.2.5: “Standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be used.” GRADE B.
* Revised Recommendation 1.2.5: “Standardised ASD assessment interviews and schedules should be used.” GRADE B.

Rationale: Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.

* Original Recommendation 1.2.7: “The assessment of intellectual, adaptive and cognitive skills associated with autism, Asperger syndrome and ASD should be seriously considered and, where possible and appropriate, formally assessed.” GRADE B
* Revised Recommendation 1.2.7: “The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed.” GRADE B

Rationale: The words “assessment of” were removed as redundant in the sentence structure. Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.

* Original Recommendation 6.2: “Education and training of local health care professionals in the administration of standardised autism, Asperger syndrome and ASD assessment interviews and schedules should be provided. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established.” GRADE C
* Revised Recommendation 6.2: “Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established..” GRADE C

Rationale: Wording of the first sentence was altered to improve readability and to recognise that not only “local health care professionals” may administer assessment tools. Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.

* Original Recommendation 6.3: “Norms should be developed for autism, Asperger syndrome and ASD assessment tools specifically for the New Zealand population.” GRADE C
* Revised Recommendation 6.3: “Norms should be developed for ASD assessment tools specifically for the New Zealand population.” GRADE C

Rationale: Words “autism, Asperger syndrome and” removed. Under DSM-5, DSM-IV specified subtypes including autism and Asperger syndrome are subsumed under the one condition of autism spectrum disorder.

Table 3. Revised recommendations relevant to diagnostic classification of people with ASD

|  |  |  |
| --- | --- | --- |
| Original Reference | Revised recommendation | Grade |
| 1.2.5 | Standardised ASD assessment interviews and schedules should be used. | **B** |
| 1.2.7 | The intellectual, adaptive and cognitive skills associated with ASD should be seriously considered and, where possible and appropriate, formally assessed. | **B** |
| 6.2 | Professionals administering standardised ASD assessment tools should be provided with appropriate training. When reporting the results of ASD-specific tests, caution should be exercised as New Zealand norms have not yet been established. | **C** |
| 6.3 | Norms should be developed for ASD assessment tools specifically for the New Zealand population. | **C** |

New recommendations

Two new good practice points were developed by the LGG (see **Table 4**).

**New Good Practice Point 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. GRADE **✔**

Rationale: This Good Practice Point was proposed to reflect evidence in the review relating to how cultural, social, demographic and economic factors have been shown to influence access to and process of diagnostic classification under DSM-IV [43].

**New Good Practice Point 1.2.15**: Decisions about whether to undertake an assessment of an individual should elicit and consider whether that person requires, would value, and would benefit from a diagnosis of ASD. GRADE **✔**

Rationale: the LGG wanted it recognised that decisions about assessment should consider whether a person wants or sees the need for a clinical diagnosis, and that such factors be discussed in determining whether to pursue a formal diagnosis.

Table 4. New recommendations relevant to diagnostic classification of people with ASD

|  |  |  |
| --- | --- | --- |
| Reference | New good practice points | Grade |
| 1.2.14 | Assessment should consider the influence of diversity such as ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographical location. | **✔** |
| 1.2.15 | Decisions about whether to undertake an assessment of an individual should elicit and consider whether that person requires, would value, and would benefit from a diagnosis of ASD. | **✔** |

Appendix 1: Methods

This appendix describes the living guideline update process and includes details on:

* the living guideline group (LGG) team
* review scope and methodology
* recommendation development processes.

A1.1 Contributors

Living Guideline Group members

**Matt Frost (Chair)**

New Zealand Disability Support Network

**Matt Eggleston (Deputy Chair)**

Child and Adolescent Psychiatrist, Clinical Head, Child and Family Specialty Service, Canterbury District Health Board

**Jill Bevan-Brown**

Associate Professor, School of Curriculum and Pedagogy, College of Education, Massey University

**Tanya Breen**

Consultant Clinical Psychologist, Specialist in Autism Spectrum Disorder and Disability Issues, Clinical Consultant for Altogether Autism, Hamilton

**Sally Clendon**

Senior Lecturer, Speech Language Therapy Programme, Institute of Education, Massey University

**Debbie Fewtrell**

General Practitioner (special interest in autism spectrum), Kerikeri

**Andrew Marshall**

Developmental Paediatrician, Child Development Team at Puketiro Centre, Porirua and Clinical Leader, Child Health, Wellington Hospital

Ex-officio LGG members:

**Joanna Curzon[[6]](#footnote-6)**

Team Leader – Research, Autism Spectrum Disorder (ASD) National Team, Special Education, Ministry of Education

**Natasha Gartner**

ASD Project Manager, Family and Community, Disability Support Services, National Services Purchasing, National Health Board, Ministry of Health

INSIGHT Research team

**Marita Broadstock**

Director, INSIGHT Research Ltd, Living Guideline Group Project Manager and lead researcher

Declarations of competing interest

None

Acknowledgements

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INSIGHT Research and the LGG thanks members of ASK Trust who, as participants in the consultation process relating to a draft version of this report, provided detailed suggestions and new references which have been incorporated into section 2.4 “Cultural implications”.

Also thanked are Ministry of Education Library staff for their assistance in retrieval of articles pertinent to this review.

A1.2 Review scope

The current review updates evidence on diagnostic classification of ASD evident in the development and publication of the DSM-5 and the implications of the evidence for the New Zealand ASD Guideline [[1](#_ENREF_1)].

The original searching for the guideline was performed in July 2004.

Consistent with earlier updates produced for the Living Guideline Group, the search was limited to articles published in the English language on or beyond January 1 2004.

A1.3 Research question

The Living Guideline Group identified the changes to diagnostic classification relevant to ASD in the DSM-5 as a priority topic to update with respect to implications for the NZ ASD Guideline [[1](#_ENREF_1)].

RESEARCH QUESTION: "What are the implications for the NZ ASD Guideline of the DSM-5’s changes to diagnostic classification relevant to ASD?

A1.4 Search strategy

Systematic database searching was designed and conducted by INSIGHT Research.

Database searches were conducted on 10 May 2013 and updated 9 August, 2013. Website searches were conducted between September and November 2013. Full search strategies are available upon request.

Searches were limited to English language publications from January 2004 or later.

The search strategy had three components:

* core research material from the APA’s dedicated website: [www.dsm5.org](http://www.dsm5.org);
* empirical studies, reviews, commentaries and discussion papers from bibliographic and review databases; and
* position statements and featured commentaries from selected prominent clinical and autism websites.

A1.5 Source material

DSM-5 website

Research considered specifically by the APA in developing the DSM-5 were sourced from the DSM-5 website: [www.dsm5.org](http://www.dsm5.org)

Sources from this site included:

* Research planning conference summaries and monographs [[19](#_ENREF_19)] including that relating to the Autism and Other Pervasive Developmental Disorders Conference [[22](#_ENREF_22)]
* DSM-5 field trials [119]
* Publications relating to DSM-5 development [120]
* Commentarties and responses [[18](#_ENREF_18)]
* Online assessment measures [121]

Databases

Critiques, commentaries and discussion papers relating to the topic were also sought through a systematic search of major databases.

Searches included autism search terms in addition to explicit mention of DSM-5 (or variants thereof) in the publication’s title, abstract, or keywords.

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

* Medline & PreMedline
* Embase
* CINAHL
* PsychINFO
* PsychARTICLES
* Psychology and Behavioural Science collection
* SocINDEX
* Web of Science (ISI Web of Knowledge)
* Cochrane Database of Systematic Reviews
* Cochrane Methodology Register
* Cochrane Register of Controlled Trials
* Database of Abstracts of Reviews of Effects (DARE)
* Health Technology Assessment (HTA) Database
* National Health Service Economic Evaluation (NHS EED).

Searching of references of publications retrieved in the course of the review was conducted.

#### Hand searching of journals and contacting of authors for unpublished research was not undertaken in this review.

Key websites

Targeted grey literature searching was conducted to access position statements and featured commentaries on the topic from prominent websites in New Zealand, Australia, UK, US and Canada. Websites were identified with the assistance of the LGG Chair and included prominent autism advocacy, support and/or research communities and organisations. The goal was to provide an indication of the range of issues debated by major stake-holders as background to the formal published literature.

A1.6 Review synthesis

The review provides a narrative, critical synthesis of sourced material relating to the changes in the diagnostic classification of ASD in DSM-5 which may potentially impact existing ASD Guideline’s recommendations.

Key areas included in the review include:

* Summary of the DSM-5 diagnostic criteria for ASD and how these differ from DSM-IV-TR criteria
* Rationale for changes to DSM-5’s diagnostic criteria for ASD
* Critical summary of empirical trials relevant to the reliability and validity of the changes to DSM-5’s classification system, including APA field trials
* Summary of key issues identifed relating to the potential clinical, research, and social impact (including identity, support, etc) of DSM-5’s changes in diagnostic criteria for ASD.

A1.7 Preparing recommendations

Developing recommendations

A one-day face-to-face meeting was held on 26 November 2013 where the LGG considered the findings of the current review and revised or developed new recommendations for the original ASD Guideline [[1](#_ENREF_1)]. Using their collective professional judgement and experience, the LGG discussed the body of evidence with respect to the research questions and the applicability of the evidence within New Zealand.

Developing recommendations involves consideration of the whole evidence base for each of the research questions. The quality and consistency of the evidence and the clinical implications of the evidence within a New Zealand context is weighed up by all the LGG members. The recommendations were agreed by consensus during the meeting.

Grading recommendations

Each recommendation is assigned a grade to indicate the overall ‘strength of the evidence’ upon which it is based. Strength of the body of evidence is determined by three domains [122]:

* 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).

It should be noted that systematic reviews and meta analyses (secondary studies) considered drawing on publications over an overlapping timeframe could report on (some of) the same studies. For this reason it is important to be aware that the results from secondary studies should not be summated as independent sources of evidence as this would misrepresent the quantity of studies and give shared primary studies undue weight.

The grades of recommendations used by the Living Guideline Group, also used in the original ASD Guideline [[1](#_ENREF_1)], are presented in **Table A1.2**.

A1.8 Consultation

Seeking comments from stakeholders is vital for peer-review and quality assurance processes in developing the report. In a focused consultation 13 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 New Zealand services and needs, clarity, and ease of use of the report. In addition, organisations were explicitly asked to provide any position statements or commentaries on the implications of DSM-5 that they have produced where these have not been already identified in grey literature searching.

Responses were received from 7 organisations and individuals, including: Autism New Zealand, Altogether Autism, ASK Trust, the Ministry of Education, individual responses from two members of the New Zealand Psychological Society, the New Zealand Paediatric Society, and the Royal Australian and New Zealand College of General Practitioners.

It should be noted that whilst the New Zealand Psychological Society did not make formal submission, the feedback provided by two of its individual members was informed by the Society’s position statement on DSM-V: http://[www.psychology.org.nz/Position\_Statements](http://www.psychology.org.nz/Position_Statements)

Feedback was positive with all groups approached supporting the draft report in general terms, with only two offering more significant suggestions.

The lead researcher collated feedback and drafted revisions for the LGG to consider. Amendments were finalised by group consensus. Suggestions identified in the consultation led to improvements to the final report, particularly with respect to comments by ASK Trust relating to Section 2.4 (Cultural implications). Changes included refining use of terminology, and the addition of new references to reinforce and better illustrate some of the issues raised. INSIGHT Research and the LGG are grateful to those individuals and organisations who participated in the consultation process.

Table A1.2. Guide to grading recommendations [[1](#_ENREF_1)]

|  |  |
| --- | --- |
| 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 |
| Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. | |
| Good practice point | Grade |
| Where no evidence is available, best practice recommendations are made based on the experience of the Living Guideline Group or feedback from consultation within New Zealand. | **✓** |
| Note: Good practice points are the opinion of the Living Guideline Group, or developed from feedback from consultation within New Zealand where no evidence is available. | |

Appendix 2: Abbreviations and glossary

A2.1 Abbreviations and acronyms

Miscellaneous Terms

ADD attention-deficit disorder

ADHD attention-deficit/hyperactivity disorder

APA American Psychiatric Association

AS Asperger syndrome

ASD Autism Spectrum Disorder

CI confidence interval

HFA High Functioning Autism

HTA Health Technology Assessment

ICD International Classification of Diseases

INSIGHT Research Independent Network of Specialists in Guidelines & Health Technology Research

LGG Living Guideline Group

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

NZGG New Zealand Guidelines Group

NHMRC National Health and Medical Research Council (Australia)

NIH National Institute of Health (US)

NIMH National Institute of Mental Health (US)

NZ New Zealand

PDD Pervasive Developmental Disorder

PDD-NOS Pervasive Developmental Disorder – Not Otherwise Specified

RCT Randomised controlled trial

ROC Receiver Operating Characteristic

RRB Restricted, repetitive patterns of behaviour

SCD Social (Pragmatic) Communication Disorder

Se sensitivity

Sp specificity

SR Systematic review

UK United Kingdom

US United States of America

vs versus

WHO World Health Organisation

wk/s week/s

Tests, scales and measures

|  |  |
| --- | --- |
| ADI-R | Autism Diagnostic Interview-revised |
| ADOS-G | Autism Diagnostic Observation Schedule-Generic |
| BDI-2 | Battelle Developmental Inventory, Second Edition |
| CARS | Childhood Autism Rating Scale |
| CASD | Checklist for Autism Spectrum Disorder |
| DISCO | Diagnostic Interview for Social and Communication Disorders |
| DSM-IV-TR | Diagnostic and Statistical Manual of Mental Disorders – version 4 (text revision) |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders – version 5 |
| M-CHAT | Modified Checklist for Autism in Toddlers; |
| PBS | Pediatric Behavior Scale |
| RDoC | Research Domain Criteria |
| SRS | Social Responsiveness Scale |
| SCQ | Social Communication Questionnaire |

Databases

|  |  |
| --- | --- |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| DARE | Database of Abstracts of Reviews of Effects |
| Embase | Excerpta Medica Database |
| HTA Database | Health Technology Assessment Database |
| Medline | Medical Literature Analysis and Retrieval System Online |
| NHS EED | National Health Service Economic Evaluation Database |
| PsycINFO | Psychology Information Database |
| SocINDEX | Sociology Research Database |

A2.2 Glossary

Epidemiological and statistical terms

Aetiology

The cause of a condition

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

Biological markers

A measureable biological characteristic that can be used as an indicator of a particular condition

Comorbid condition

One that exists at the same time as another condition in the same individual. The two conditions are usually independent of each other. For example a child who has autism might also develop leukaemia. That the child has autism complicates treating the leukaemia, but the two conditions are independent of each other

Co-morbidities

Conditions which occur in association with another condition (e.g., ASD) more commonly than in the general population

Confirmatory factor analysis

A statistical approach used to test whether the data fit a hypothesised model of the nature of a construct (or factor)

Construct validity

The validity of inferences that observations or measurement tools actually represent or measure the construct being investigated. Subtypes include convergent validity and discriminant validity

Convergent validity

Refers to the degree to which two measures of constructs that theoretically should be related, are in fact related. A subtype of construct validity

Dimensional measures

Dimensional measures give an indication of how much a condition affects an individual

Discriminant validity

Tests whether concepts or measurements that are supposed to be unrelated are, in fact, unrelated. A subtype of construct validity

Factor analysis

A statistical method used to describe variability among observed, correlated variables in terms of a potentially lower number of unobserved variables called factors

False negative

A false negative test result is one that does not detect the condition when the condition is present

False positive

A false positive test result is one that detects the condition when the condition is absent

Generalisability

Applicability of the results to other populations

Gold reference standard

Refers to a diagnostic test or benchmark that is the best available under reasonable conditions

Grounded theory

Grounded theory refers to a set of systematic inductive methods for conducting qualitative research aimed toward theory development

Incidence

The number of new events (new cases of a disease) in a defined population, within a specified period of time

Kappa

Percentage agreement between two raters/measures with chance agreement taken into account

Latent class analysis

A statistical technique (a subset of structural equation modeling) used to find groups or subtypes of cases in multivariate categorical data. These subtypes are called "latent classes"

Latent profile analysis

Latent profile analysis is concerned with deriving information about categorical latent variables from the observed values of continuous manifest variables. In other words, LPA deals with fitting latent profile models (a special kind of latent variable models) to the measured data

Level of evidence

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

Neuroimaging

The use of various techniques to either directly or indirectly image the structure, function/pharmacology of the brain

Neurodiversity

An approach to learning and disability which suggests that diverse neurological conditions appear as a result of normal variationl 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 recognized and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status

Neuropsychological

Structure and function of the brain as related to specific psychological processes and behaviours

Phenotype

The composite of an person’s observable characteristics or traits, such as morphology, development, biochemical or physiological properties and behaviour. Phenotypes result from the expression of a person’s genes as well as the influence of environmental factors and the interactions between the two

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

Prospective

Collecting data over time, in the future

Psychopathology

The study of mental disorder, mental distress, and abnornal/maladaptive behaviour

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 epidemiological experiment in which subjects in a population are randomly allocated into groups to receive or not receive an experimental preventive or therapeutic procedure, manoeuvre, or intervention. The groups are compared prospectively

Receiver Operating Characteristic

The receiver-operating characteristic captures, in a single graph, the various alternatives that are available a criterion or threshold is moved to higher and lower levels

Reference standard

An independently applied test that is compared to a diagnostic test being evaluated in order to verify the latter’s accuracy. A reference standard therefore provides an accurate or “truth” diagnosis for verification of positive and negative diagnoses. It is sometimes described as providing “final truth determination”

Reliability

Yielding the same or compatible results in different clinical studies

Retrospective

Looking at data collected in the past

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)

Sensitivity

The probability of a positive test result in the presence of a condition which the test is designed to detect

Specificity

The probability that a diagnostic test can correctly identify a person who is free of the condition being tested for

Test-retest reliability

A measure of the degree of agreement in a test/assessment when the same patients are observed separately by two or more raters within an interval during which the clinical conditions of the patients are unlikely to have changed

True negative

A true negative test result is one that does not detect the condition when the condition is absent

True positive

A true positive test result is one that detects the condition when the condition is present

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 literature review reporting a systematic method to search for, identify and appraise a number of independent studies

Appendix 3: DSM-IV-TR criteria for Pervasive Developmental Disorders

299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2) and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, non-functional routines or rituals

(c) stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication or (3) symbolic or imaginative play

C. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder

299.80 Asperger’s Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(2) failure to develop peer relationships appropriate to developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (egg, by a lack of showing, bringing or pointing out objects of interest to other people)

(4) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(2) apparently inflexible adherence to specific, non functional routines or rituals

(3) stereotyped and repetitive motor mannerisms (egg, hand or finger flapping or twisting, or complex whole-body movements)

(4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (eg, single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interest, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes ‘atypical autism’ – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

**Source**: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Copyright 2000 American Psychiatric Association [[17](#_ENREF_17)]

Appendix 4: DSM-5 Criteria for Autism Spectrum Disorder

A4.1: DSM-5 Criteria for Autism Spectrum Disorder 299.00 (F84.0)

**A.** **Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):**

1. Deficit is in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Section A4.2).*

**B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):**

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat the same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see* ***Section******A4.2****).*

**C.** **Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).**

**D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**

**E.** **These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.**

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

***Specify* if:**

* With or without accompanying intellectual impairment
* With or without accompanying language impairment
* Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

* Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

* With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition)

(Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

A4.2: DSM-5 Severity Levels for Autism Spectrum Disorder

|  |  |  |
| --- | --- | --- |
| Severity level | Social communication | Restricted, repetitive behaviors |
| Level 1  MILD  "Requiring support” | Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful. | Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |
| Level 2  MODERATE  "Requiring substantial support” | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or  abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited  to narrow special interests, and how has markedly odd nonverbal communication. | Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in  a variety of contexts. Distress and/or difficulty changing focus or action. |
| Level 3  SEVERE  "Requiring very substantial support” | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches. | Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. |
|  | | |
| **Source**: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Copyright 2013 American Psychiatric Association [[2](#_ENREF_2)] | | |

A4.3: DSM-5 Criteria for Social (Pragmatic) Communication Disorder 315.39 (F80.89)

**A. Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:**

1. Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.

2. Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on the playground, talking differently to a child than to an adult, and avoiding use of overly formal language.

3. Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.

4. Difficulties understanding what is not explicitly stated (e.g., making inferences) and nonliteral or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

**B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.**

**C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).**

**D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains or word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.**

**Source**: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Copyright 2013 American Psychiatric Association [[2](#_ENREF_2)]

Appendix 5: DSM-5 Online Emerging Assessment Measures

For further clinical evaluation and research, the APA offers a number of “emerging measures” in Section III of DSM-5. These patient assessment measures were developed to be administered at the initial patient interview and to monitor treatment progress, thus serving to advance the use of initial symptomatic status and patient reported outcome (PRO) information, as well as the use of “anchored” severity assessment instruments. Instructions, scoring information, and interpretation guidelines are included. Clinicians and researchers may provide APA with [feedback](http://www.dsm5.org/Pages/Feedback-Form.aspx) on the instruments’ usefulness in characterising patient status and improving patient care.

These measures should be used to enhance clinical decision-making and not as the sole basis for making a clinical diagnosis. Further information on these measures can be found in DSM-5. The measures can be broadly classified into four types:

* **Cross-cutting symptom measures** may aid in a comprehensive mental status assessment by drawing attention to symptoms that are important across diagnoses. They are intended to help identify additional areas of inquiry that may guide treatment and prognosis. The cross-cutting measures have two levels: Level 1 questions are a brief survey of 13 domains for adult patients and 12 domains for child and adolescent patients, and Level 2 questions provide a more in-depth assessment of certain domains.
* **Severity measures** are disorder-specific, corresponding closely to criteria that constitute the disorder definition. They may be administered to individuals who have received a diagnosis or who have a clinically significant syndrome that falls short of meeting full criteria. Some of the assessments are self-completed, whereas others require a clinician to complete.
* The **World Health Organization Disability Assessment Schedule**, Version 2.0 (WHODAS 2.0) assesses a patient’s ability to perform activities in six areas: understanding and communicating; getting around; self-care; getting along with people; life activities (e.g., household, work/school); and participation in society. The scale is self- or informant-administered and corresponds to concepts contained in the WHO International Classification of Functioning, Disability and Health.
* The **Personality Inventories** for DSM-5 measure maladaptive personality traits in five domains: negative affect, detachment, antagonism, disinhibition, and psychoticism. For adults and children ages 11 and older, there are brief forms with 25 items and full versions with 220 items. A full version for informants is also available.

Additional assessment measures include the following:

* The **Early Development and Home Background** (EDHB) form may assist in the assessment of the early development and past and current home background experiences of a child receiving care. Two versions are provided: one to be completed by the child’s parent or guardian, and the other to be completed by the clinician.
* The **Cultural Formulation Interview (CFI)** is a set of 16 questions that clinicians may use to obtain information during a mental health assessment about the impact of culture on key aspects of an individual’s clinical presentation and care.
* The **Cultural Formulation Interview—Informant Version** collects collateral information on the CFI domains from family members or caregivers.
* **Supplementary Modules to the Cultural Formulation Interview** can help clinicians conduct a more comprehensive cultural assessment. The first eight supplementary modules explore the domains of the core CFI in greater depth. The next three modules focus on populations with specific needs, such as children and adolescents, older adults, and immigrants and refugees. The last module explores the experiences and views of individuals who perform caregiving functions.

**Source**: [121]

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1. Adapted from Halfon et al [3] Halfon N and Kuo AA. What DSM-5 could mean to children with autism and their families. JAMA Pediatrics 2013;167(7):608-13. [↑](#footnote-ref-1)
2. The DSM changed its version suffix from IV to 5 to avoid unwieldy adjuncts in updates (eg; DSM-IV-TR). [↑](#footnote-ref-2)
3. A research paper reporting on the reliability of the WHODAS 2.0 in psychiatric patients is currently in preparation (*personal communication*, Oct 25 2013, Alison Beale, DSM Research Associate, APA). [↑](#footnote-ref-3)
4. The reliability of the DSM-5 Self-rated Personality Inventory in psychiatric patients is in preparation (*personal communication*, Oct 25 2013, Alison Beale, DSM Research Associate, APA). [↑](#footnote-ref-4)
5. The ‘reactivity to sensory input’ criterion in the DSM-5 was not covered in the DSM-IV checklist. To account for the chance that some people may have met criteria for diagnosis under DSM-5 without this difference, 41 participants were excluded who met the socialisation criteria requriements but met only one criterion from the restricted interests/repetitive behaviour group. [↑](#footnote-ref-5)
6. We report with great sadness that Joanna passed away during the preparation of this research [↑](#footnote-ref-6)