

ASD in DSM-5:

What the Research Shows and Recommendations for Change

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Executive Summary

Over the course of the last several months, considerable discussion has centered around the issue of how to appropriately structure the diagnostic criteria for Autism Spectrum Disorder within the DSM-5. The Neurodevelopmental Disorders Workgroup charged with this task possesses a challenging job, requiring an effective synthesis of both a vast research literature and the use of significant clinical and policy knowledge to try to anticipate the practical consequences of different choices. In our previous policy brief, the Autistic Self Advocacy Network reviewed the potential implications of the DSM-5 draft criteria for ASD on services, supports, and accommodations for children and adults on the autism spectrum within the United States. We identified a wide variety of both positive and negative implications of the proposed shifts within the ASD diagnosis. This brief aims to expand upon this discussion by outlining a variety of the issues facing and research-backed options available to the Neurodevelopmental Disorders Workgroup as it works to complete the diagnostic criteria for ASD within the DSM-5.

To accomplish this, we have laid out our recommendations in the following sections.

FIRST, we summarize our areas of agreement and concern with the current proposal, focusing in particular on the benefits of the unified ASD diagnosis and the still present sensitivity concerns that concern our community.

SECOND, we analyze the impact of the draft criteria on under-represented groups, placing particular emphasis on adults, women and girls, and racial and ethnic minority groups.

FINALLY, we offer targeted recommendations to address these issues, proposing adjustments in the social communication domain to enhance sensitivity, the inclusion of motor and movement issues within the diagnostic criteria or accompanying text, and specific language changes to the criteria itself.

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Where We Stand on the Current Draft Criteria

Recognizing Progress: Where DSM-5 Steps Forward from DSM-IV

In several crucial respects, the draft criteria for ASD within DSM-5 constitute a sizeable improvement over the definition of the autism spectrum within DSM-IV. We believe that the unification of the disparate DSM-IV autism spectrum diagnoses into a unified ASD diagnosis under DSM-5 constitutes a positive development both from the standpoint of expanding access to service provision and as a means of showing fidelity to the research literature. Our previous policy brief analyzed the service implications of unified diagnostic criteria, finding it likely to enhance access to services and supports within several key disability policy infrastructures. Furthermore, sizeable research support exists for a unified diagnosis as well. Asperger's is only differentiated from autistic disorder by absence of language delay, but that distinction has proven invalid¹². PDD-NOS has vague, diverse criteria, so diagnosticians do not reliably agree on what it means³. The system has created so much confusion that which specific ASD diagnosis a person gets has more to do with which clinic he or she sees than ASD traits⁴. Moreover, many people appear to fit one diagnosis in a certain context or at a certain time, but then they seem to shift into another category within the autism spectrum (usually to one whose social challenges are considered less severe or subtler)⁵⁶. Therefore, removing these falsely narrow, competing diagnoses should improve access to services based on individual need and demonstrate a greater consistency with the current state of research regarding the autism spectrum.

Furthermore, the inclusion of sensory issues within domain (B) of the criteria represents a significant step forward that will likely do much to add to research and practice supporting that area of autistic experience. Additionally, an acknowledgement in the criteria presents a step forward, acknowledging that while onset must occur by early childhood, recognition of autistic traits may not occur until adolescence or well into adulthood due to more supportive and less demanding social environments. Later in this brief, we make the case that this language must be strengthened so as to more effectively identify and avoid difficulty in accessing diagnosis for adults. Nonetheless, the acknowledgement in the onset provision of the criteria that autistic traits are highly contextual in nature represents a significant step forward.

Identifying Areas of Concern

At the same time, a number of areas of potential concern have arisen regarding the draft criteria and the ways in which they are likely to be applied. We remain extremely concerned by the possibility that the shift from requiring two of four social communication traits to be met within the DSM-IV to requiring three of three within the DSM-5 would result in loss of access to the ASD diagnosis for individuals who would appropriately be considered autistic. Furthermore, we believe that this loss of sensitivity is likely to be particularly profound with regards to adolescents and adults, women and girls, and other underserved groups. We believe that the introduction of the Social Communication Disorder diagnosis may compound this problem. While we do not object to the merging of the social interaction and communication domains (reflecting that most items for both in DSM-IV have a social nature⁷), we are somewhat concerned that this may result in inadequate attention to speech (e.g., audiovisual integration)^{8,9,10,11,12} and language¹³ issues, as recent reviews suggest that structural (beyond social) language problems are core across the spectrum^{14,15}.

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Furthermore, we have profound concerns regarding the introduction of a severity scale for the DSM-5 ASD diagnosis, from the perspective of both research and practice. As we have stated previously, the use of a severity scale as a measure of treatment outcomes would likely result in clinicians inappropriately discouraging autistic traits as an emphasis of intervention (i.e: preventing handflapping, encouraging eye contact, working to re-direct from focused interests, etc.) rather than focusing on functional skills with more direct impacts on quality of life. In addition, significant concern exists that a severity scale will be utilized to deny access to service provision for some adults and children on the autism spectrum.

ASD traits have little direct relationship with adaptive functioning, yet people on the autism spectrum tend to have substantial impairment in daily living and other adaptive skills^{16,17,18}. As a group, adults on the autism spectrum tend to have a lower employment rate than adults with intellectual disabilities¹⁹ as well as a lower rate of independent living compared with other adults with developmental disabilities and comparable cognitive abilities^{20,21}. The gap between IQ and adaptive functioning is higher with greater age and IQ^{22,23,24,25,26,27,28,29}, and IQ similarly is not a good measure of functioning for people on the autism spectrum³⁰. Those on the autism spectrum with fewer or milder ASD traits and higher IQ may tend to experience greater anxiety, depression, and victimization,^{31,32,33,34} likely because of others' perceptions of them as more responsible for their problems and lower support^{35,36}. Indeed, following high school, people on the autism spectrum without intellectual disabilities tend to lose more services^{37,38} and in young adulthood their developmental improvements slow or stop (for example, their ASD traits, relationship with their mother, and community daytime activities), while young adults on the autism spectrum with intellectual disabilities tend to continue to improve in these areas of functioning^{31,39,40}. This highlights that ASD is too complex for linear continua or spectra, as suggested by a severity scale; social context and support as well as other factors can mask or compensate for behaviors or functional challenges.

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Social Communication: Context and Compensation

Studies comparing the inclusiveness of DSM-V with that of the DSM-IV criteria for ASD^{43,44,45,46,47,48,49,50,51}, have usually suggested that the DSM-5 would reduce the number of people qualifying for an ASD diagnosis across the autism spectrum and lifespan^{52,53,54,55,56,57,58,59}. Many of these studies have used old data, one problematically — and most famously — using a sample from 1993 based on the comparison between DSM-III and DSM-IV⁶⁰. As the Workgroup has noted^{61,62}, such studies cannot have had full access to the proposed breadth of criteria and examples. Yet at least two recent studies recruited within the development of the DSM-5 and still found the same result with this improved methodology^{63,64}. It appears that people on the autism spectrum correctly diagnosed with PDD-NOS tend to have narrower but deeper social deficits than people diagnosed with Autistic Disorder or Asperger's,⁶⁵ and that as proposed significant risk exists that such individuals may be moved off of the autism spectrum^{66,67,68}.

Diagnostic practices for ASD, even when using leading instruments, may struggle to capture the nuances of challenges people on the autism spectrum face. To standardize diagnoses and train people to reliably agree on how to interpret behavior, diagnostic instruments (including those described as “semi-structured”) tend to involve more structured interactions than the more demanding, dynamic interactions involved

in real life⁶⁹. This is true when comparing interactions with adults in diagnostic versus natural settings,⁷⁰ even though people on the autism spectrum as children and adolescents tend to communicate and relate better with adults than peers^{71,72,73}. People on the autism spectrum, including as children, tend to have competence with basic socio-emotional demands but struggle with those that are more complex,^{74,75} and whether the ASD field's standard methods sufficiently capture the complexities of the variable social contexts and life stages is debatable. For example, some leading diagnostic instruments for ASD lump together adolescents and adults, mainly testing on young adults and under, and even when they improve their ability to recognize people on the autism spectrum they may do so at rates considered unsatisfactory^{76,77}.

As another example, people on the autism spectrum tend to present with uneven skill sets leading to overly optimistic impressions of our skills in public. Several studies have shown that children and adolescents on the autism spectrum tend to engage in more externalizing (e.g., aggressive, hyperactive, meltdown) behavior around their parents than others^{78,79,80}. Teachers similarly tend to rate their ASD students' social skills more favorably than the parents, or otherwise report them differently, with much more agreement among parents and teachers of typically developing students^{81,82,83}. This is generally because of higher expectations in public and among strangers, and greater motivation around peers, but the effort to behave appropriately or fit in exhausts our resources and we become dysregulated in private, among family members who tend to be more understanding^{84,85}. Adolescents and adults on the autism spectrum in published research and elsewhere have described a need to "pass" for "neurotypical" or otherwise mask our natural behaviors to appear more normal, with varying degrees of effectiveness^{86,87,88,89,90,91}. These behaviors include both those classified in the social and behavioral domains of the ASD diagnosis, such as repetitive movements that many of us learn to selectively bring under our control because of stigma⁹².

Most people on the autism spectrum can at least partially compensate behaviorally despite experiencing continued underlying struggles because of having severe deficits in implicit (automatic, unconscious, spontaneous) social cognition but abilities in explicit (effortful, conscious, systematic) social cognition^{93,94,95,96,97,98,99,100,101,102,103}. Implicit social cognition includes sensorimotor (embodied) perception, such as in "reading" nonverbal cues (like facial expressions and other body language or movement),^{104,105} and people tend to struggle with this throughout the spectrum and lifespan^{106,107,108,109}, even those who no longer appear autistic behaviorally in some diagnostic assessments,¹¹⁰ although some learn (e.g., "reading" eyes) intellectually¹¹¹. Similarly, many children on the autism spectrum can only understand others' basic movements when they have access to contextual information¹¹² or imitate when they have explicit information like goals¹¹³. Therefore children and adults on the spectrum often can perform social or other tasks when effortful¹¹⁴ or prompted^{115,116}.

As these explicit social cognitive skills require some attention and executive functioning or reasoning abilities,^{117,118,119} people on the autism spectrum often perform better in research on their cognitive flexibility^{120,121} in addition to social skills (e.g., competent "reciprocity" skills in the lab by preadolescence¹²²) than they do in daily life, as these artificial, formal (diagnostic) settings might prime us to certain expectations and motivations, especially as we gain awareness and experience over time. Thus, under clinical examination a person on the autism spectrum might apply more conscious attention and effort that would be too difficult or unlikely in "real-life" situations. In short, many reactions or instincts that most people might process

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automatically and unconsciously, are for those of us on the autism spectrum more likely to be done in a deliberate and conscious fashion, leading to a greater likelihood of functional deficits or other challenges as a result of the laborious effort associated with such learned behavior.

These nuances help to explain why people on the autism spectrum's social communication deficits have a greater tendency to reduce over time, while the repetitive and restricted behaviors and interests are more stable — a pattern found throughout life^{123,124,125,126,127,128}.

To address the likelihood that these characteristics of ASD may impair the sensitivity of the diagnosis, ASAN has proposed two primary recommendations regarding social communication:

- Shift the number of traits required to meet the Social Communication Domain of the ASD diagnosis from three of three to two of three. Our preference is that this be done across the lifespan, reflecting the challenges of identifying inherently contextual traits in clinical settings. However, should the Workgroup not be willing to pursue this route, we propose that the criteria be shifted to two of three specifically for adolescents and adults age 14 and above.
- Linking the Social Communication Disorder diagnosis to the autism spectrum.

While the Workgroup has noted the wide range and examples within the three of three (down from two of four) social criteria, in both an academic journal commentary¹²⁹ and a presentation at the recent IMFAR conference¹³⁰ it has generally only specifically mentioned the nonverbal and relationship subdomains. We find the reciprocity subdomain to be the most problematic for the purposes of sensitivity. Its listing as the first aspect of ASD, replacing the current nonverbal cues subdomain (an order we would like to keep) poses significant challenges. The examples offered for reciprocity are the most stringent; moreover, while the social communication criteria have wide *ranges* of examples, the RRBI criteria more flexibly have various *types* of examples. A deficit in reciprocity, of course, cannot lie in just one person^{131,132,133} and thus it is likely that many individuals who would appropriately qualify for a diagnosis in childhood and adulthood would be denied as a result of the reciprocity domain. Indeed, a significant minority of children, with a higher proportion for adolescents and adults, struggle to meet criteria years after an initial evaluation, especially in social reciprocity¹³⁴. **Thus, we propose a shift in the social communication domain from requiring three of three sub-domains to requiring only two of three.**

In our previous brief, we stated our concerns regarding the potential negative impacts on service provision of locating Social Communication Disorder diagnosis outside of the autism spectrum. This diagnosis, which essentially classifies people who appear to meet the social communication but not repetitive, restricted behaviors and interests domains of ASD,¹³⁵ has drawn considerable controversy¹³⁶. There is little to no data on the validity, reliability, or prevalence (frequency) of this newly proposed diagnosis,¹³⁷ for which specific criteria¹³⁸ only appeared very recently after its proposed creation last year. It has huge overlaps with the PDD-NOS diagnosis even though the Workgroup has stated that the DSM-5 ASD diagnosis is intended to cover that current

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subgroup^{139,140}. Yet two studies^{141,142} that attempted to specify PDD-NOS found that the vast majority of people correctly diagnosed with it do not demonstrate the range of behaviors to qualify for DSM-IV Autistic disorder or Asperger's diagnoses, with about half to nearly all of them having significant social communication traits but apparently milder or no significant behavioral (RRBI) traits. This is unsurprising given that PDD-NOS allows qualifying behaviors to be subthreshold, fewer, or otherwise unlike (atypical, including late onset) those in autistic disorder^{143,144}. Despite this, as elaborated upon in ASAN's previous policy brief, individuals with a diagnosis of PDD-NOS are currently eligible for a wide variety of different types of service provision and legal protections that they would not be able to access as easily in a non-ASD related Social Communication Disorder diagnosis.

PDD-NOS is the most common ASD diagnosis,^{145,146} at least in children, and it proves that the traits and needs of people on the autism spectrum are too diverse to fit neat boxes. This is a systemic problem with the DSM-IV, which for most of its diagnoses includes great within-group diversity, overlap between diagnoses, and tendency for people to meet criteria for multiple diagnoses, and thus includes many catch-all NOS diagnoses^{147,148}. DSM-5 attempts to resolve this issue in part by encouraging more simultaneous diagnoses, for example ASD alongside ADHD and anxiety,¹⁴⁹ which is often helpful but insufficient. In other areas, the Workgroup has recognized the ongoing need for NOS-like diagnoses by proposing "Not Elsewhere Classified" diagnoses for the intellectual disability, ADHD, and motor disorder categories¹⁵⁰. Furthermore, not enough is known theoretically or empirically to explain the qualitative significance of the addition of restrictive, repetitive behaviors to social communication deficits¹⁵¹. It is worth noting that other neurodevelopmental categories have multiple types and subtypes of diagnoses (e.g., motor disorders)¹⁵².

Thus, we recommend exploring ways to link the Social Communication Disorder diagnosis to the broader autism spectrum, possibly by renaming it as ASD-Not Elsewhere Classified or ASD-Social Communication subtype. We recommend that it use the current SCD criteria or the Social Communication criteria of the proposed ASD diagnosis with the relaxation to two of three criteria. This strategy will allow the Workgroup to achieve its goal of differentiating those individuals without RRBI from the main focus of the ASD diagnosis, while also ensuring that individuals likely to be shifted to a diagnosis of Social Communication Disorder will retain the practical and research benefits of a connection to the broader autism spectrum.

Recognizing and Addressing the Needs of Under-Represented Groups: Adults, Women and Girls, and Racial and Ethnic Minorities

Enhancing the sensitivity of the ASD diagnosis is particularly relevant as a mechanism to ensure that individuals on the autism spectrum from traditionally under-represented groups, such as women and girls, adults, and racial and ethnic minorities, are more likely to be identified, a concern the Workgroup shares¹⁵³. We urge the Workgroup to incorporate specific considerations of these under-represented groups in the accompanying text to the ASD diagnosis, and to consider the ways in which the position of historically under-represented groups makes the earlier recommended changes to the diagnostic criteria particularly important.

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Adults

Adulthood offers unique challenges for individuals on the autism spectrum. The shift to a more typical expectation of independence and the relative lack of structure, combined with the frequent removal of natural and formal supports, pose much higher demands on adaptive functioning. Young adulthood offers unique challenges, as the transition to typical “milestones” of adulthood is difficult for everyone and change is challenging for people on the autism spectrum. As a result, access to a diagnostic category that can help enhance access to service provision, supports, and legal protections can be critical for adults on the autism spectrum, including middle-aged and older adults who have gone undiagnosed to date^{154,155}.

In previous communications, the Workgroup has stated that the DSM-IV does not work well for young adults, perhaps emphasizing an age group that has received more research attention;^{156,157} we firmly believe the DSM-IV criteria have not worked well for adults across the lifespan, including middle-aged and older adults, as well. The DSM-IV’s widening of the autism spectrum has been sufficiently recent that large numbers of adults on the autism spectrum are still unidentified. Many have learned to superficially compensate and often lack documentation of their early history. Concerns exist that the current proposal may exacerbate these problems.

A few key measures can work to help mitigate these concerns, among them a) the previously cited recommendations regarding shifting to two of three criteria in the social communication domain, b) clarifying that a history of meeting the social communication or restrictive, repetitive behavior criteria should be sufficient to qualify an individual to access a diagnosis as well as other language edits focused specifically on making the criteria more accessible across the lifespan. For example, the criteria’s acknowledgement that traits “may not become fully manifest until social demands exceed limited capacities” is an important acknowledgement of the reality of later diagnosis for adolescents and young adults, but fails to take into account the experiences of those who have developed coping mechanisms and other “mitigating measures” as a means of masking ASD related traits.

Explicitly acknowledging that learned behavior, coping mechanisms and other “mitigating measures” should not be considered against an individual being evaluated for an ASD diagnosis would help address these concerns for middle-aged and older adults, as well as some younger individuals. Furthermore, since many such adults may not possess a developmental history, clarifying in accompanying text that one may not be necessary in circumstances where it may not be obtainable for practical reasons would be a helpful development.

Women and Girls

ASD is much more commonly diagnosed in males, and much evidence suggests it is underdiagnosed in women and girls. Although many have long thought that the male: female ratio is greater in people with intellectual disability, several recent studies suggest minimal or no sex differences in overall cognitive functioning^{158,159,160,161}. Women and girls appear to have subtler, milder, or otherwise somewhat different traits. These may include fewer restricted and repetitive or stereotyped behaviors^{4,162} and less severe social communication deficits^{163,164}. Females have more likelihood of pretend play¹⁶⁵ and

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friendship¹⁶⁶ in childhood, and by adolescence when with friends more time spent in conversation — rather than playing video games like boys¹⁶⁷. Indeed, women and girls may often have interests that are considered more social and less characteristic of ASD, even if they engage in them in an ASD-typical (intense) way¹⁶⁸.

As adolescents, perhaps from a combination of more social demands (but also opportunities from more explicit teaching of social skills), social awareness, and attempted “masking” of autism, females may be more likely to have internalizing disorders such as anxiety and depression¹⁶⁹. Females in general tend to have more social pressure to cope with their problems in relatively contained ways, such as internalization, while boys are more likely to be allowed to act out more aggressively,^{170,171} which might make autistic males’ problems more noticeable¹⁷². Similarly, by adulthood females may be much more likely to be able to superficially imitate typical behaviors to suppress ASD traits, no longer appearing to behaviorally qualify as clinically on the autism spectrum despite their clear history and current deficits on ASD-related tasks¹⁷³.

Females are less likely to be diagnosed with ASD than males even when they have similar traits and both meet criteria^{174,175,176}. Prevalence studies in the general population suggest that autistic girls and women are especially underdiagnosed^{177,178}. Females diagnosed with ASD may tend to be diagnosed later in life than males, and be more likely to receive other diagnoses first¹⁷⁹. Females in general are less likely to have language delays, and such delays are likely to bring clinical attention such as a diagnosis of ASD¹⁸⁰. These problems can only contribute to the alienation that many women on the autism spectrum experience¹⁸¹. Females are underrepresented in ASD research, which can skew understanding of how ASD manifests in females and the provision of services and interventions for them^{182,183,184,185}.

Explicit acknowledgement of these issues within the accompanying text would constitute a significant step forward for women and girls on the autism spectrum.

Racial and Ethnic Minorities

ASD has long been diagnosed at a lower rate in African Americans, Latinos, and Native Americans than in white people in the U.S., with similar trends for racial and ethnic minorities globally^{186,187,188,189,190,191,192,193,194,195,196,197,198,199,200}. Despite this, actual ASD rates likely do not vary significantly between groups. While ASD had long been diagnosed more frequently in — and the ASD field has tended to be dominated by — upper middle-class white people, research has shown ASD not to be more common in people of greater socio-economic status, with one recent study suggesting the opposite²⁰¹. Instead, factors such as enhanced identification, awareness, and service availability largely account for differences in diagnostic rates²⁰². These factors continue to improve, as research has found that socio-economic status poses a decreasing barrier to ASD diagnoses in some areas^{203,204} and the recent U.S. report of a higher diagnosed rate of ASD especially in African Americans and Latinos²⁰⁵ both indicate an encouraging trend toward better service accessibility for these underserved groups.

Besides factors like family income and attitudes toward medical and clinical practices, challenges with assessment often relates to linguistic diversity. Not enough clinicians or doctors are bilingual or culturally competent, and may have difficulty

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differentiating ASD-related communication issues from language difficulties common among English language learners^{206,207}. This is particularly evident in the alarmingly greater diagnostic rate of ASD in the U.S. for Latino children of U.S.-born parents compared to those of foreign-born parents²⁰⁸.

Cultural differences are likely to impact ASD diagnosis. For example, Asian Americans, along with many other non-Western communities, have social conventions (e.g., regarding eye contact) that may challenge traditional interpretations of ASD's diagnostic criteria. Avoiding eye contact is abnormal in the West and typical of ASD but appropriate in many other cultures when communicating with someone of higher status,^{209,210} yet some ASD diagnostic instruments in East Asia emphasize eye contact²¹¹. This and other cultural differences may help to explain the relative inconsistency of diagnostic rates for Asians and Asian Americans^{212,213}. (Showing further complexity of behaviors associated with social communication, for people on the autism spectrum looking at the mouth may build communicative competence,²¹⁴ and for people generally avoiding eye contact offers certain cognitive advantages^{215,216}.)

To help address these problems, we recommend changing “eye contact” to “eye gaze” and from that social communication deficits occur “across contexts” to “in multiple contexts”.

What qualifies as “normal” (especially in terms of social communication) varies by society and culture. Shockingly few cross-cultural studies and studies on racial and ethnic minorities have been conducted in the ASD field despite the diagnosis' emphasis on social deficits, so far too little is known in this area. No one wants otherwise disadvantaged groups to also be underserved regarding ASD, and we urge caution to reach the goal we share with the Workgroup, improving access to diagnoses and services for racial and ethnic minorities. Failure to address these issues in the DSM-5 ASD criteria may reverse recent gains and pose further access barriers for racially and ethnically diverse communities.

Motor and Movement Issues

A growing body of evidence supports the inclusion of motor and movement issues within the ASD diagnosis. The repetitive motor movements already in the diagnosis signify, in part, a form of self-regulation in response to poor motor control²¹⁷, but are only one symptom of this broader issue. Indeed, a recent consensus paper argues that the cerebellum, a brain region responsible for motor control, is atypical in and central to ASD²¹⁸. Neuroscientists, movement scientists, occupational therapists, speech language pathologists, and others often recognize these problems, including understanding their pervasive effects^{219,220,221}. These significant problems in smooth movement and motor functioning appear to occur in 80 to 90 percent of people on the autism spectrum^{222,223}, a rate that will likely prove higher with the DSM-5 criteria because of its greater requirement of repetitive, restricted behaviors. While the Workgroup has suggested that the DSM-5 would encourage developmental coordination disorder (DCD) to be diagnosed with ASD,²²⁴ motor deficits' great frequency and robust relationship to social communication deficits^{225,226,227,228,229} suggest that this may be an insufficient approach. Motor and movement challenges in ASD often center on specific types of motor function rather than a broad diagnosis like DCD.

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People on the autism spectrum commonly display gross motor problems such as clumsiness and uncoordinated gait (as emphasized by the DCD diagnosis),²³⁰ postural control^{231,232} and fine (hand and arm) motor deficits^{233,234}. These traits appear “core” to ASD. Challenges with “body posture” and “gesture” are not limited to social interaction, as implied by the DSM-IV criteria. One prominent line of research has shown that deficits in ASD in using skilled movements and gestures to command, imitate, and use tools strongly contribute to motor, social, and communication deficits in ASD^{235,236,237}. Such research has also shown that people on the autism spectrum rely on feedback from our own bodies rather than visually to learn new movements, a slower and less accurate way of learning that contributes to social communication deficits^{154,155,238,239,240}. Indeed, fine motor deficits relate to receptive and receptive language problems in people on the autism spectrum, a relationship not found in typical people²⁴¹.

The Workgroup need not worry that adding motor deficits to the ASD diagnosis would increase the autism spectrum, as few non-autistic siblings²⁴² and people in the broad autism phenotype²⁴³ share them and the specific deficits mentioned here are not involved in ADHD, another developmental disability with atypical movement^{244,245}. Rather, they appear to contribute importantly to the within-group variability of autistic people. They improve the accuracy and stability of the ASD diagnosis for young children^{246,247,248} and like related sensory issues,²⁴⁹ motor deficits may improve the ASD’s diagnosis’s ability to accurately include without harming its ability to exclude non-autistic people. Similarly, they may improve early diagnosis of ASD, as these problems often emerge for people on the autism spectrum before language develops in typically developing children^{250,251,252,253,254,255,256}.

Ultimately these movement and motor issues functionally impact various areas of life, such as handwriting²⁵⁷; social or physical recreational activities^{258,259,260,261} especially those involving ball skill;²⁶² daily living skills;²⁶³ and increased maladaptive behaviors²⁶⁴. They are highly quantifiable²⁶⁵, and external manifestations of some of the sensory processing deficits that are more difficult to measure^{266,267}. Including motor deficits in the ASD diagnosis would encourage further research on them, and more immediately and practically, would help to inform assessment and interventions, such as addressing the current under-provision of services for motor issues²⁶⁸, and increasing embodied forms of therapy that may improve communication^{269,270}.

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Summary of Main Recommendations for ASD Diagnostic Criteria

A) We recommend that the Workgroup shift the social communication of the ASD diagnosis from three of three to two of three subdomains. Should this not be accepted, we recommend that the Workgroup implement such shift for individuals age 14 and above, acknowledging the lack of inclusion of older adolescents and adults in the field trial data.

B) We urge the Workgroup to incorporate Social Communication Disorder within the broader autism spectrum as a subtype of ASD (i.e: ASD-Not Elsewhere Classified or ASD-Social Communication subtype). The Workgroup may wish to consider incorporating the SCD diagnosis as is, or engage in a slight tightening first by matching SCD’s criteria with the social communication domain of the ASD diagnosis, as amended by other recommendations.

C) We urge the Workgroup to add motor and movement challenges to domain (B) as another subdomain and shift the criteria to require two of five as compared to two of four criteria. Should this not prove feasible, we urge the Workgroup to clarify in the accompanying text that sensory input can include the vestibular (balance) and proprioceptive (perception of body position) senses,^{271,272,273} and that motor and movement issues are exceedingly common in individuals on the autism spectrum.

D) We urge the Workgroup to eliminate the severity scale attached to ASD. Should this not prove feasible given the DSM-5's broader orientation, we urge the Workgroup to ensure that: a) the accompanying text clarify specifically that the severity scale is not intended as a measure of treatment outcomes or as a means of evaluating an individual for eligibility for service provision, and b) shift the RRBI section of the severity scale to focus on issues relating to flexibility (an issue with concrete and meaningful implications to quality of life), rather than implicitly encouraging clinicians to redirect individuals on the autism spectrum from focused interests and repetitive behaviors.

Proposed Edits to Specific Language within the ASD Diagnostic Criteria

One reason for the controversies and conflicting analyses of the sensitivity issues within DSM-5 is that the main text of the ASD diagnosis is not always interpreted flexibly by clinicians, a particular danger with the number of possible combinations of subdomains to an ASD diagnosis proposed to narrow from 2,027 in the DSM-IV to 11 in the DSM-5²⁷⁴. Although the Workgroup has discussed utilizing accompanying text to help address this issue and should pursue that approach, it is likely that language outside the main criteria will not be read by many clinicians and as such is an insufficient remedy. A number of independent studies finding significant drops in sensitivity between DSM-IV and DSM-5, particularly for individuals without intellectual disabilities, have indicated the critical importance of examples in the text and how they are interpreted. Thus, we put forward the following suggested language changes.

Workgroup members have previously stated that the examples provided in the diagnostic criteria are non-exhaustive, only one example per criterion is needed, and that for social communication people may qualify by challenges in either behavior or understanding²⁴. We urge explicit clarification of this in the criteria. We suggest below that the examples not be listed as closed and linear. Furthermore, the Workgroup recently said that people may qualify by history rather than their current status³². Similarly, we suggest direct acknowledgment of the role of compensation and have suggested a description of impairment more in line with other diagnoses.

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Autism Spectrum Disorder

Examples provided are non-exhaustive.

- A. Deficits in use or understanding of social communication and social interaction in multiple contexts, not accounted for by general developmental delays, and manifest by at least two of the following:
1. Deficits in nonverbal communicative behaviors used for social interaction; (such as poorly integrated verbal and nonverbal communication, abnormalities in eye gaze and body-language, deficits in understanding and use of nonverbal communication, unusual or lack of use of facial expression or gestures).
 2. Deficits in social-emotional reciprocity; (such as abnormalities in social approach or back and forth conversation, reduced sharing of interests, emotions, and affect and response, or reduced likelihood of initiation of social interaction).
 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); (such as difficulties adjusting behavior to suit different social contexts, difficulties in sharing imaginative play and in making friends, or apparent reduced interest in people).
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning, or extreme distress at small changes).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. 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).
 5. Motor deficits in performance of skilled movement not limited to social communication (such as manual dexterity, postural control or balance, ball skills)
- C. Traits must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities, or may become masked by learned behavior or other mitigating measures). Criteria may be met by history rather than current presentation or functioning.
- D. Traits cause clinically significant impairment in social, occupational, or other important areas of functioning.

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Conclusion

As the Workgroup repeatedly articulated at its recent IMFAR presentation, a key responsibility and goal in the DSM-5 process should be to “do no harm”, a long standing principle of the medical profession as a whole. Evidence-based interventions (e.g., behavioral and developmental therapies) tend to have relatively low risk compared with some more medical (e.g., invasive) practices for other diagnoses, and may even help non-autistic people²⁷⁵. Thus an ASD diagnosis’ main potential benefit and risk are, respectively, access to services and the threat of stigma²⁷⁶. We and many others in the Autistic and autism communities seek to ensure continued access to services, as well as to reduce stigma of ASD, and we believe the DSM-5 has the potential to help in both regards²⁷⁷.

Clinicians and other practitioners, family members, and self-advocates share priorities on the diagnosis of the autism spectrum. Clinical diagnoses place a higher priority on sensitivity (not under-diagnosing people on the autism spectrum in this case), while researchers emphasize specificity (guarding against diagnosing non-autistic people with ASD)²⁷⁸. Thus the researchers who provide the evidence base of the autism spectrum have often placed greater emphasis on ensuring the complete exclusion of all non-autistic people than on correctly including all those who would be appropriately classed within the ASD diagnosis, raising some doubt about the representativeness of research for less obvious individuals. Many researchers also want to link the diagnosis to biology, but because not enough is known about this area, the ASD diagnosis will continue to be based on behavior, promoting clinical usefulness important for accessing services²⁷⁹. Like clinicians, relatives and self-advocates also tend to place particular importance on sensitivity, as the public conversation over possible implications of the DSM-5 for ASD has demonstrated.

Addressing these community concerns over sensitivity can also help to protect the interests of researchers. For example, the separation of Social Communication Disorder from ASD would mark a historic departure in ASD’s classification that could disrupt international research. The classification of the autism spectrum (or “Pervasive Developmental Disorders”) has many similarities in the U.S.-based system (DSM-IV) and the World Health Organization’s International Classification of Diseases (ICD-10), which has assisted with the ability to compare research findings across countries. Yet the ICD-11, also currently under development, proposes multiple diagnoses within the ASD category²⁸⁰. This would further distance the connection between the autism spectrum in the DSM and ICD, as the ICD already has a more relaxed set of pervasive developmental disorders that includes the vague diagnoses of Atypical Autism, Pervasive Developmental Disorder — Unspecified, and Other Pervasive Developmental Disorders. Integrating SCD into ASD may prevent further barriers by continuing the ability to interpret literature based on the two main diagnostic systems.

The history of the revision process for ASD in the DSM-5 offers reason for optimism that constructive community engagement may contribute to improvements in the diagnostic criteria. The draft of the ASD criteria posted in February 2010 would have missed an even more substantial number of people on the autism spectrum in some ways²⁸¹ than a headline-grabbing article²⁸² did months ago. A study analyzing those criteria found that most participants without intellectual disabilities diagnosed with an ASD in the current DSM-IV-R, including all those diagnosed with Asperger’s, could not be diagnosed with the proposal then for the DSM-5^{283,8}. The Workgroup relaxed

We hope that ASAN’s series of memos, alongside other community input, assists in the effort to complete the criteria for sensitive ASD classification that ensures that people access the support they need for quality of life.

the criteria somewhat in its subsequent draft (last updated in January 2011), and analyses based on this latest draft have raised significant concerns about the need for further revision. We hope that ASAN's series of memos, alongside other community input, assists in the effort to complete the criteria for sensitive ASD classification that ensures that people access the support they need for quality of life. We appreciate the Workgroup's ongoing engagement with our community and look forward to continued discussion and collaboration.

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