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BRIEF REPORT

Brief Report: DSM-5 "Levels of Support:" A Comment on Discrepant Conceptualizations of Severity in ASD

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Abstract Proposed DSM-5 revisions to the diagnosis of autism spectrum disorder (ASD) include a "severity" marker based on degree of impairment. Although qualitative differences between support levels are described, quantitative methods or practice recommendations for differentiating between levels remain undetermined. This leaves the field vulnerable to potential discrepancies between severity categorizations that may have inadvertent service implications. We examined overlap between mild, moderate, and severe impairment classifications based on autism symptoms, cognitive skills, and adaptive functioning in 726 participants (15 months—17 years) with ASD. Participants with mild, moderate, and severe autism symptoms demonstrated varying levels of adaptive and cognitive impairment. These discrepancies highlight the need for a clearly elucidated method of classifying level of support in ASD diagnosis.

Keywords Autism · Severity · Diagnosis · DSM-5

Introduction

Proposed revisions to the DSM-5 include dimensional assessments intended to allow clinicians to rate both the presence and severity of psychiatric and related symptoms within diagnostic categories (American Psychiatric Association 2013). With regard to the diagnosis of autism spectrum disorder (ASD), proposed revisions include a severity marker based on degree impairment in the domains of social communication and restricted and repetitive behaviors. Although qualitative differences between impairment levels are described in the proposed text (DSM-5; American Psychiatric Association 2012), quantitative methods or practice recommendations for differentiating between these levels have yet to be publicized. The most recent revision of the Autism Diagnostic Observation Scale—Second Edition (ADOS-2; Lord et al. 2012a) provides guidelines for calculating overall level of autism symptoms relative to others with ASD of the same age and language level using a rubric called Comparison Scores (CS). However, the extent to which CS, DSM-5 Severity levels, and measures of adaptive and functional impairment overlap is unclear. It is also unclear how DSM-5 ASD severity differentiations may change according to age and developmental level or how they will impact individuals' eligibility for and access to services across systems of care. Determining how these severity labels will be applied is therefore an important question for diagnosticians and researchers alike.

Currently, a tension exists between proposed research criteria for determining symptom severity and clinical operationalization of the same. Proposed DSM-5 autism spectrum criteria includes three severity classifications: Level 1 ("Requiring support"), Level 2 ("Requiring substantial support"), and Level 3 ("Requiring very substantial support") (American Psychiatric Association 2012). These classifications are split across two areas, Social Communication (SC) and Restricted and Repetitive Behaviors (RRB), mirroring core ASD symptoms. Severity

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metrics now exist for the separate ADOS-2 Social Affect (SA) and RRB domains (Hus et al. 2012), and the authors note that the extent to which these separate domain severity scores map onto the proposed DSM-5 levels of support warrants exploration. In contrast to approaches that split the two domains, traditional markers of severity, such as the Global Assessment of Functioning scale (American Psychiatric Association 2000), have focused more on overall level of functional impairment in everyday living, particularly as measured by cognitive and adaptive functioning across settings. Previous findings suggest that the overlap between autism symptoms and cognitive and adaptive functioning is weak (e.g., Kanne et al. 2011), yet as described in an editorial by (Bernier 2012), no defined criteria exists by which to weigh the importance of these different variables when making severity determinations. Additionally, when conceptualizing severity, clinicians and researchers may differ in their focus on "core" (ASD-specific) versus "associated" (self-injury, language ability) symptoms. This may arise due to differences in what they are trying to describe (e.g., neurobiological mechanisms versus everyday functioning for a specific individual; Bernier 2012).

The notion of "level of support" might be thought of as comparable to severity of impairment in that both reference, either explicitly or implicitly, the environmental modifications necessary for daily functioning. Currently, the methods by which clinicians and researchers operationalize severity largely depend on individual preference, background, and training (Lord et al. 2012b). Without a standard method or measure, it is unlikely that we are consistent across professionals in controlling for age and language level when making severity distinctions. Yet the wide variability in these factors within the autism spectrum, and their known impact on most definitions of severity (Bernier 2012), necessitates controlling for them. One measure that attempts to do this is the ADOS-2 Comparison Score (CS). The CS converts ADOS-2 raw total scores to reflect level of autism symptoms in comparison to others of the same age and language level. The CS has been developed as a means of clarifying the contribution of autism-specific symptoms to individual profiles of functioning. Thus, although not a global measure of functional impairment, the CS is intended to refine how ASD symptoms in particular are understood to contribute to the larger context of impairment in an individual child. In conjunction with the ADOS-2, clinicians are encouraged to use cognitive and adaptive behavior measures with standardized clinical cut-offs to determine severity of impairment within children with autism diagnoses (Lord et al. 2012a).

It remains unclear how ADOS-2 severity labels (high, moderate, low, or minimal level of autism-related symptoms) will map onto the diagnostic levels proposed by the DSM-5. It is similarly unclear where adaptive and cognitive functioning fit into this new diagnostic picture. The diagnostic process can be extremely stressful for parents (Goin-Kochel et al. 2006; Warren and Stone 2011), and many of them are concerned about their children's future levels of functioning (Nissenbaum et al. 2002). Because previous diagnostic categories will now be subsumed under the single label of ASD, the question of mild, moderate, or severe impairment likely will be even more central in parents' minds. The lack of congruence between ADOS-2, DSM-5, and other common criteria for designating impairment in ASD leaves the field vulnerable to discrepancies between severity categorizations reminiscent of current discrepancies between diagnostic categories (such as Asperger's Syndrome and Autistic Disorder), which originally contributed to the push for a revised diagnostic schema.

This descriptive study sought to examine how severity categorizations in a large clinical research sample differ when cognitive, adaptive, or autism symptom severity scores are used to classify level of impairment. We compared the frequency with which participants classified as mild, moderate, or severe on autism symptoms, cognitive skills, or adaptive behavior were classified at similar or discrepant levels of impairment on the other two indices.

Methods

Participants were drawn from a university-based regional autism registry database. From September 2010 to October 2011, 1,290 families consented to have their clinical data added to the registry and to be contacted for future research across a variety of clinical and research initiatives. Of these families, 726 participants (ages 15 months—17 years; $M = 5.86$, $SD = 3.78$; 84 % male) had diagnostic data available that included autism symptoms, cognitive skills, and adaptive behavior as measured at a single time point. Using data drawn from clinical and research records, we segmented clinical profiles of cognitive, adaptive, and autism symptoms across ranges of severity. We then compared these profiles to determine how they might correspond across severity categorizations.

Measures

Autism Symptoms

All participants completed the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2000). The ADOS is a semi-structured standardized clinical observation system that measures social, communication, and repetitive behaviors associated with autism. The Comparison Score

Table 1 Means (SD) and Ns for mild, moderate, and severe impairment across cognitive, adaptive, and autism symptom groups

	Mean (SD)				
Impairment group	IQ	Vineland ABC	CS	SA	RRB
Mild-to-no	102.95 (13.13)	90.55 (5.88)	3.67 (0.73)	2.57 (0.68)	1.00 (0.00)
	n = 243	n = 65	n = 27	n = 21	n = 15
Moderate	78.76 (3.81)	76.9 (4.03)	6.35 (0.68)	4.70 (0.46)	5.00 (0.00)
	n = 103	n = 310	n = 298	n = 83	n = 44
Severe	53.75 (6.68)	62.98 (6.25)	9.13 (0.82)	7.89 (1.41)	8.53 (1.30)
	n = 380	n = 351	n = 401	n = 622	n = 667

IQ intelligence quotient, *Vineland ABC* vineland adaptive behavior composite, *CS* ADOS-2 comparison score, *SA* ADOS-2 social affect severity score, *RRB* ADOS-2 restricted and repetitive behavior severity score

based on age and language level was generated from this instrument. We used cutoffs that correspond to the ADOS-2 CS, with scores of 1–4 indicating no worse than mild autism symptoms, 5–7 moderate autism symptoms, and 8–10 high levels of autism symptoms (Lord et al. 2012a). Following the guidelines established by Hus et al. (2012), we also created calibrated severity scores for the ADOS-2 subdomains of Social Affect (SA) and RRB. Because there is not a published set of severity cut-offs for SA and RRB, we used the same cut-offs as the CS scale (1–4, 5–7, 8–10) upon which they are based.

Adaptive Behavior

Adaptive behavior was assessed by the Vineland Adaptive Behavior Scales—Second Edition (VABS-II; Sparrow et al. 2005), a parent interview that assesses Social, Communication, Daily Living, and Motor Skills. It provides standard scores for these domains as well as an overall Adaptive Behavior Composite ($M = 100$, $SD = 15$). Cutoffs used for data analysis were consistent with those listed in the VABS manual: severe impairment, <71; moderate impairment, 71–84, and mild to no impairment, >84.

Cognitive Skills

Multiple measures were used to assess cognitive ability. These included the Mullen Scales of Early Learning (Mullen 1995), Stanford-Binet—V (Roid 2003), Wechsler Intelligence Scale for Children—IV (Wechsler 2003), Wechsler Preschool and Primary Scale of Intelligence—Third Edition (WPPSI-III; Wechsler 2002), Bayley Scales of Infant Development—Second Edition (Bayley 1993), Differential Ability Scales- II (DAS-II; Elliott, 2007), Leiter-R (Roid and Miller, 1997), and Kaufman Brief Intelligence Test (K-BIT; Kaufman and Kaufman 1990). Cutoffs used for data analysis were severe impairment: <71, moderate impairment: 71–84, and mild to no impairment: >84. These cut-offs were based on standard accepted ranges of intellectual disability and borderline intellectual disability (American Psychological Association 2000).

Analyses

Grouping labels of mild, moderate, and severe impairment were compared for consistency across the measures used to define level of impairment: cognitive skills (IQ), adaptive behavior (VABS), overall autism symptom severity (CS), social communication impairment (SA), and restricted and repetitive behavior impairment (RRB). We then graphed these comparisons by depicting the breakdown of participants with severe, moderate, and mild CS/SA/RRB scores within the severe, moderate, and mild-to-no impairment VABS and IQ groups.

Results

Mean values for cognitive, adaptive, and autism symptoms across the mild-to-no, moderate, and severe impairment groups are presented in Table 1. Examining overall CS, the concordance between labels was highest for severe–severe-severe (n = 179, 24.7 %), with far fewer consistent ratings for moderate–moderate-moderate (n = 25, 3.4 %) and mild–mild-mild (n = 2, 0.3 %). After consistently "severe," the next most common ratings were: severe IQ, severe VABS, moderate CS (n = 80, 11 %); mild IQ, moderate VABS, severe CS (n = 71, 9.8 %); and mild IQ, moderate VABS, moderate CS (n = 64, 8.8 %). Values in the other categories ranged from 0.3 to 7.7 %, underscoring the inconsistencies in severity of impairment across cognitive skills, adaptive behavior, and autism symptoms.

These inconsistences are depicted in Fig. 1. Across each row, graphs are split by adaptive (left) and cognitive (right) skills. Within graphs, each bar represents mild, moderate, or severe adaptive or cognitive impairment. The shaded groups within each bar depict how many participants had mild, moderate, and severe impairment in CS (first row),

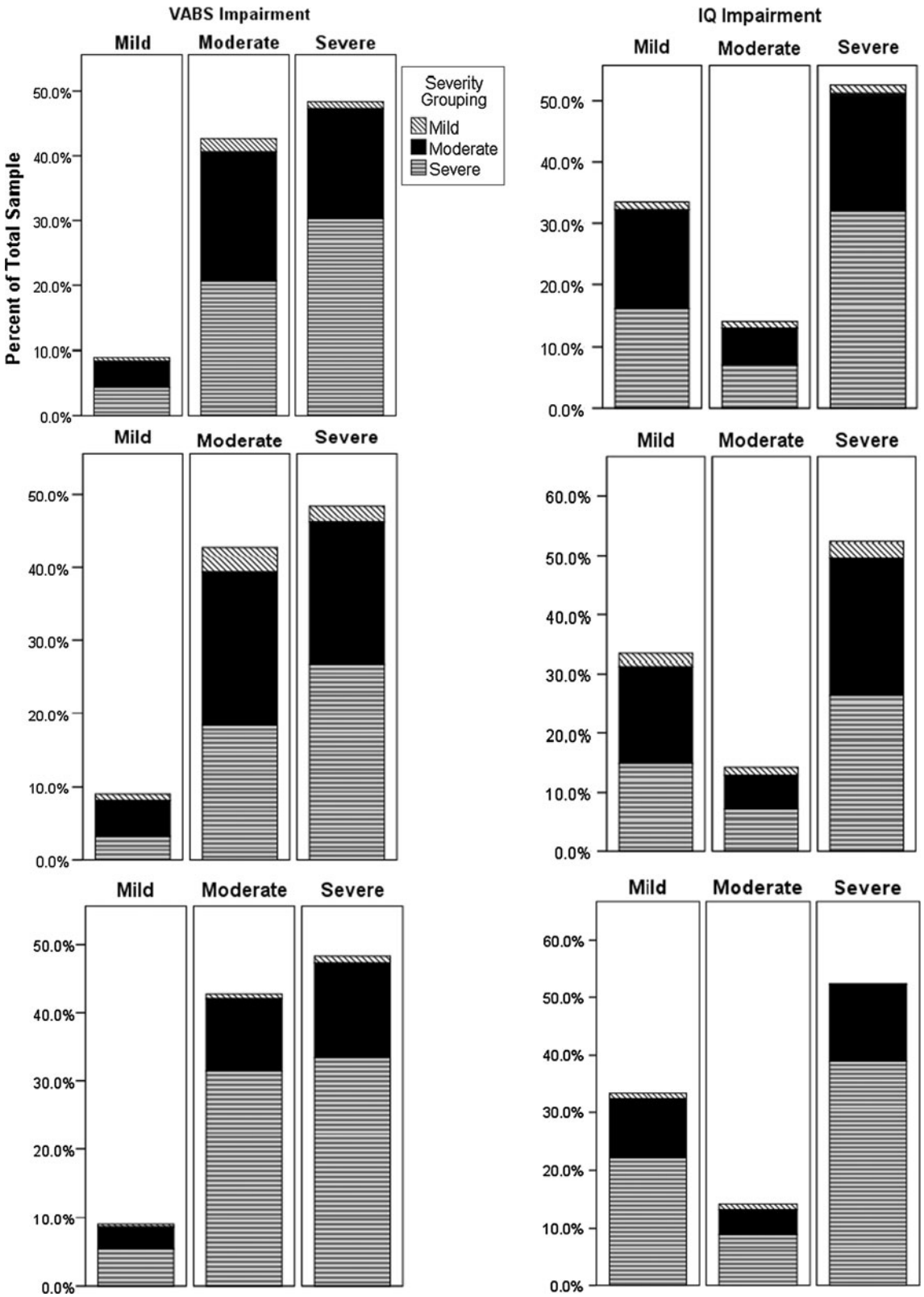

Fig. 1 Levels of adaptive (*left*) and cognitive (*right*) impairment by, *top* to *bottom*: *row 1*, total ADOS-2 comparison score; *row 2*, ADOS-2 social affect severity score; *row 3*, ADOS-2 restricted and repetitive behavior severity score

SA (second row), and RRB (third row), as spread across adaptive and cognitive impairment categories. Variations in shading show the inconsistencies in severity scores that emerged for CS, SA, and RRB. The majority of participants had severe impairment within these categories, but their cognitive and adaptive impairments were spread across the mild, moderate, and severe ranges.

Discussion

Discrepancies emerged in the distribution of severity categorizations across adaptive and cognitive functioning and autism symptomatology. This is consistent with previous work (e.g., Kanne et al. 2011; Gotham et al. 2009) and makes conceptual sense given the theoretical underpinnings and practical measurement of these constructs. However, these findings illustrate that it is not clear how individuals with mixed levels of impairment across cognitive, adaptive, and autism-specific symptom domains would be classified in terms of DSM-5 "Level of Support" using existing measures of severity related to the autism spectrum. The differences found in our severity classifications highlight the need for a clearly elucidated method of classifying an ASD diagnosis as needing mild, moderate, or significant levels of support according to proposed diagnostic labels. Without an established method, it will be difficult to interpret what these support modifiers mean when they are assigned according to site- and provider-specific criteria. Additionally, further study is warranted of how those designations may change with development.

In theory, the proposed DSM-5 severity labels, by considering level of support required, will incorporate some level of functional and/or cognitive impairment. This creates the potential for the diagnostic modifier to be influenced by co-occurring symptoms and impairments that, although related to ASD, are not part of its core symptom profile. If that is the intended use of DSM-5, as a field we must be clear about how we use and interpret the "level of support" modifier, given that it is not specific to autism symptoms. Alternatively, if forthcoming DSM-5 text clarifies that the diagnostic modifier should indicate "level of support" for ASD symptoms alone (i.e., should *not* overlap with functional impairment), the issue then becomes how to quantify and qualify that going forward. It will be critical for the field to take a unified approach to the use of such qualifiers, although how that consensus is reached and information is disseminated has yet to be decided. As dimensional severity ratings are proposed throughout DSM-5 (APA 2013), professionals in other fields of study likely will face similar issues; some fields already may provide valuable precedents for uniform application of DSM criteria across researchers and service providers.

This work has several limitations, primarily that it is descriptive in nature. Because it is cross-sectional, it does not capture changes in functioning over time. What it does capture is the inconsistency across cognitive, adaptive, and autism symptom severity markers across a broad age range of participants. The questions that this raises about forthcoming diagnostic practices do not have clear answers. Both researchers and clinicians should consider the implications of classifying an individual as needing an unspecified "some" support versus a "substantial" level of support. This is particularly important in terms of how parents and intervention providers gauge the needs and future potential of newly diagnosed children, as well as re-evaluated adolescents and adults. More active discussion of how to operationalize DSM-5 "level of support" labels stands to improve the reliability of this aspect of future ASD diagnosis and, in so doing, may help avoid repeating our history of site-specific applications of ASD categories.

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Conflict of interest Katherine O. Gotham receives royalties for the Autism Diagnostic Observation Schedule, 2nd edition; all royalties from clinics and projects in which she is involved are donated to charity.

References

American Psychatric Association. (2012). *DSM-5 Development: Autistic disorder*. Retrieved 10 July 2012 from http://www.dsm5.org/ProposedRevisions/.

American Psychatric Association. (2013). *DSM-5 Frequently asked questions: can you describe the dimensional assessments that are being considered for DSM-5?* Retrieved 10 March 2013 from http://www.dsm5.org/about/Pages/faq.aspx#3.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders,* (4th ed., tr). Washington, DC: Author.

Bayley, N. (1993). *Bayley scales of infant development* (2nd ed.). San Antonio, TX: The Psychological Corporation.

Bernier, R. (2012). *How do we measure autism severity?* SFARI Viewpoints. Retrieved July 2012 from http://sfari.org/news-and-opinion/viewpoint/2012/how-do-we-measure-autism-severity.

Elliott, C. D. (2007). *Differential ability scales* (2nd ed.). San Antonio, TX: Harcourt Assessment.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*, 439–451.

Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(5), 693–705. doi:10.1007/s10803-008-0674-3.

Hus, V., Gotham, K., & Lord, C. (2012). Standardizing ADOS Domain scores: Separating severity of social affect and restricted and repetitive behaviors. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-012-1719-1.

Kanne, S. M., Gerber, A. J., Quirmbach, L. M., Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2011). The role of adaptive behavior in autism spectrum disorders: Implications for functional outcome. *Journal of Autism and Developmental Disorders, 41*, 1007–1018.

Kaufman, A. S., & Kaufman, N. L. (1990). *Kaufman brief intelligence test: Manual*. Circle Pines, MN: American Guidance Service.

Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Jr, Leventhal, B. L., DiLavore, P. C., et al. (2000). The autism diagnostic observation schedule-generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*, 205–223.

Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., & Bishop, S. L. (2012a). *Autism diagnostic observation schedule (ADOS-2): manual* (2nd ed.). Los Angeles: Western Psychological Services.

Lord, C., et al. (2012b). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry, 69*(3), 306–313. doi:10.1001/archgenpsychiatry.2011.148.

Mullen, E. M. (1995). *Mullen scales of early learning*. Circle Pines, MN: American Guidance Service.

Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities, 17*, 30–43.

Roid, G. H. (2003). *Stanford-binet intelligence scales, examiner manual* (5th ed.). Itasca, IL: Riverside.

Roid, G. M., & Miller, L. J. (1997). *Leiter international performance scale—revised: Examiners manual* . Wood Dale, IL: Stoelting Co.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales, (Vineland-II)*. Circle Pines, MN: American Guidance Services.

Warren, Z. E., & Stone, W. L. (2011). Clinical best practices: Diagnosis and assessment of young children. In D. Amaral, G. Dawson, & D. Gerschwind (Eds.), *Autism spectrum disorders* (pp. 1269–1280). New York: Oxford University Press.

Wechsler, D. (2002). *Wechsler preschool and primary scale of intelligence* (3rd ed.). San Antonio, TX: Harcourt Assessment, Inc.

Wechsler, D. (2003). *Wechsler intelligence scale for children—fourth edition administration & scoring manual*. San Antonio, TX: Psychological Corporation.