

Original Investigation

What *DSM-5* Could Mean to Children With Autism and Their Families

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The American Psychiatric Association will update its *Diagnostic and Statistical Manual of Mental Disorders* to its fifth edition (*DSM-5*). With this new edition, the classification and diagnostic criteria for the spectrum of autistic disorders will change and become more specific and potentially more restrictive. Rather than maintaining several subcategories of autism including Asperger syndrome, there will be one new category called *autism spectrum disorder*. This change may alter which children are diagnosed as having autism as well as modify eligibility for treatment, educational, and other support services. We review the history and rationale for the proposed changes as well as several recent studies that have attempted to gauge the impact of these changes on children and families. We also consider how the proposed changes are likely to create new challenges for parents who are attempting to organize their children's care and for pediatricians who are providing that care and assisting with care coordination.

JAMA Pediatr. 2013;167(7):608-613. doi:10.1001/jamapediatrics.2013.2188
Published online May 3, 2013.

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According to the current version of the *Diagnostic and Statistical Manual of Mental Disorders* (fourth edition, text revision; *DSM-IV-TR*),¹ autism spectrum disorders (ASDs) are a group of developmental disabilities characterized by impairments in social interaction and communication as well as by restricted, repetitive, and stereotyped patterns of behavior. The proposed shift in the diagnosis classification of the spectrum of autism disorders in the soon-to-be-released fifth edition of the *DSM* (*DSM-5*) is creating understandable concern among parents of children with ASD. Any change in diagnostic classification can be disruptive in many ways. Children previously diagnosed as having ASD may no longer have the diagnosis and thus not qualify for needed services. Identifying a potentially new group of children with ASD may require new services and other changes in our complex child health care system. In this article, we consider the potential impact of the proposed diagnostic changes and what they could mean to children and families as well as the pediatricians who provide primary care for this growing population of vulnerable children.

Autism Prevalence

The prevalence of autism has increased rapidly since the 1970s, when prevalence estimates suggested that 1 in 2000 children were affected. Autism rates had increased from 1 in 200 by the late 1990s to 1 in 86 by 2007 and now to 1 in 50, as reported by the Centers for Disease Control and Prevention for 2011-2012.²⁻⁴ While a substantial portion of the reported time trend remains unexplained, a growing num-

ber of empirical studies suggest that changes in diagnostic definitions (eg, the publication of *DSM-IV*⁵ in 1994), diagnostic accretion (ie, children who start with a diagnosis of mental retardation also gain a diagnosis of ASD), and diagnostic expansion (ie, where children at the higher end of the functional spectrum are included) have contributed to rising incidence and prevalence rates.⁶⁻¹⁰ One recent study using administrative data from the California Department of Developmental Services to tease out age, cohort, and period effects showed that the odds of being diagnosed as having high-functioning autism among the 2002 cohort were 14.6 times the odds among the 1992 cohort.¹¹ The empirical literature also suggests that increased awareness of signs and symptoms as well as increases in risk factors (eg, older parental age at birth, higher rates of maternal obesity in pregnancy) are also associated with time trends.¹²⁻¹⁵ The increases have certainly been confounded by changing administrative, policy, and programmatic practices as well as how symptoms are interpreted by clinicians owing to a range of social, educational, and clinical reasons.^{6,9,16,17} Even so, recent surveillance estimates from the Autism and Developmental Disabilities Monitoring Network—all based on the same criteria and approach—show that the 2008 estimate of diagnosis in 1 in 88 children aged 8 years represents a 23% increase in prevalence since 2006 and a 78% increase since 2002.² After accounting for changes in diagnostic definition, diagnostic accretion, and diagnostic expansion as well as changes in awareness, administrative policies, and program policies, the incidence of autism seems to be increasing due to changes in some recognizable and yet to be defined risks.

Current Trends

Identification of ASD is improving, occurring both earlier in toddlers and later in adolescents and adults. New screening tests have been developed and deployed with reasonable levels of performance, and interventions are taking place at progressively younger ages with increasingly positive outcomes, especially for children with milder forms of ASD.^{18,19} Disparities in access to services and related disparities in outcomes continue.²⁰⁻²³ While a growing number of genes and de novo duplications and deletions associated with autism are being identified, the wide range of locations for these putative genetic markers suggests a very heterogeneous set of genetic influences that is consistent with the heterogeneity of the ASD phenotypes.²⁴ As is the case in other complex disorders with varying phenotypic expression, such as diabetes mellitus and cardiovascular disease, there is growing evidence that ASD is mediated by a network of genes that are modulated during fetal and early development.²⁵ Importantly, the cost of care for the growing number of diagnosed children is rising rapidly.²⁶

Being diagnosed as having autism, Asperger syndrome, or the less precise pervasive developmental disorder (PDD) not otherwise specified under the current *DSM-IV-TR* has great practical, clinical, psychological, cultural, economic, and even political significance. From a practical and clinical standpoint, the diagnostic classification determines who gets and is likely to benefit from treatment. From a psychological standpoint, it provides parents and children some sense of closure and, because prognosis is related to diagnosis, can result in some reduction in anxiety. For other parents, the diagnosis opens the door to greater anxiety as they face a fragmented set of treatment, educational, and family support services with unclear eligibility, transitions, and handoffs. From a cultural standpoint, diagnosis relates to what anthropologist Paul Rabinow, PhD, termed *biosociality*, or the formation of groups around biological identities based on shared or common biological conditions.²⁷ From an economic standpoint, setting thresholds based on diagnostic criteria is how state-run health care systems and insurance companies ration care. From a political standpoint, it is how people organize themselves to exert political advocacy on behalf of those who share this burden.

Possible Impact of *DSM-5*

The fifth edition of the *DSM* is scheduled for release in May 2013. In addition to the scientific rigor the committee brought to the *DSM-5* revision deliberations, they also considered the burgeoning prevalence trends. Therefore, improving diagnostic specificity to increase the positive predictive value of *DSM-5* criteria was an important goal. The committee decided that the category of PDD will be replaced with ASD, a summary term for a not yet understood combination of social communication deficits and repetitive or restricted behaviors and interests that form a pattern of behaviors that synergistically interact. Current diagnostic subcategories (autistic disorder,

Asperger syndrome, and PDD not otherwise specified) will be eliminated in favor of a consideration of the dimension of core features as well as cross-cutting factors such as language delay and cognitive development. Three symptom domains—social, communication, and atypical behaviors—will be revised. The 2 previously distinct domains of social interaction and communication behavior will become social/communication deficits, and a second domain of restrictive repetitive behaviors will incorporate all sensory symptoms. In addition, *DSM-5* will create a distinct new diagnosis of social communication disorder. This was created to include children with specific difficulties in the use of verbal and nonverbal communication that impair interpersonal relationships and social comprehension but do not fit the criteria of ASD. Among these and other changes, *DSM-5* will eliminate strict age criteria that require delays in social interaction and communication to be apparent before age 3 years. Instead, it requires that symptoms must be present at an early age but may not fully manifest until social demands exceed the child's capacities to respond. Lastly, *DSM-5* expects that the constellation of symptoms meeting the new criteria together must limit and impair everyday function (the changes are summarized in the **Table**).

Those not acquainted with the arcane details of the *DSM* might perceive the shift proposed for the autism spectrum between *DSM-IV-TR* and *DSM-5* as a radical departure. However, this shift needs to be viewed in the context of the history of the *DSM*. Until 1980, when *DSM-III*²⁹ was released, the *DSM* was largely beholden to the world view of psychoanalytically trained psychiatrists. With *DSM-III*, in an attempt to harmonize the *DSM* with medical diagnostic criteria and guarantee insurance reimbursement, classification categories were consolidated around specific criteria based on presumed etiologies.³⁰ While *DSM-IV* further sharpened this categorical approach to classification, *DSM-5* will take another quantum leap, embracing a more dimensional approach to diagnosis that considers functional dimensions (eg, communication, aggression) as a developmental continuum and uses newer measurement tools to specify functional capacities. Regarding autism specifically, although Kanner³¹ first described infantile autism in 1943, the condition was not recognized until publication of *DSM-III* in the late 1970s. In 1987, *DSM-III-R*³² expanded on *DSM-III*'s narrow focus on infantile autism to include disturbances of social interaction, communication, and behaviors. In *DSM-IV*, a more explicit categorical approach was adopted, using PDD as the umbrella category that includes the subcategories autistic disorder, Asperger syndrome, and PDD not otherwise specified.

Proponents of the new *DSM-5* ASD classification argue that it recognizes that autistic disorder and Asperger syndrome are part of the same spectrum and provides more specific criteria to evaluate the dimensions of behavioral function. In fact, recent studies that have compared historical clinical diagnosis from the *DSM-IV* field trials suggest that the specificity of the new *DSM-5* criteria is quite high (approximately 95%), yet the same studies also showed that the sensitivity is reduced dramatically.³³⁻³⁶ Those who endorse the new criteria also point out that *DSM-IV-TR* did not serve women and toddlers well and

Table. Summary of Proposed *DSM-5* Criteria Changes^a

	Change From <i>DSM-IV-R</i>	Change To <i>DSM-5</i>
Title	Autistic disorder	Autism spectrum disorder
No. of criteria	12	7
Minimum criteria	6	5
No. of domains	3	2
Social Interaction Domain Combined With Communication to Form New Domain: Social Interaction and Social Communication		
Minimum required	≥2 of 4	All 3
Criterion 1A	Marked impairments in the use of multiple nonverbal behaviors to regulate social interaction	Criterion A.2: deficits in nonverbal communicative behaviors used for social interaction
Criterion 1B	Failure to develop peer relationships appropriate to developmental level	Criterion A.3: deficits in developing and maintaining relationships appropriate to developmental level
Criterion 1C	A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people	(Subsumed into criterion A.1)
Criterion 1D	Lack of social or emotional reciprocity	Criterion A.1: deficits in social emotional reciprocity
Communication Domain Combined With Social Interaction to Form New Domain: Social Interaction and Social Communication		
Minimum required	≥2 of 4	All 3
Criterion 2A	Delay in, or total lack of, the ability to use spoken language	(Criterion removed)
Criterion 2B	Marked impairment in the ability to initiate or sustain a conversation with others	(Subsumed into criterion A.1)
Criterion 2C	Stereotyped or repetitive use of language or idiosyncratic language	(Subsumed into criterion B.1)
Criterion 2D	Lack of varied, spontaneous make-believe or social imitative play appropriate to developmental level	(Subsumed into criterion A.3)
Restricted Interests and Repetitive Behaviors Domain		
Minimum required	≥1 of 4	≥2 of 4
Criterion 3A	Encompassing preoccupation with ≥1 stereotyped and restricted pattern of interest abnormal in intensity or focus	Criterion B.3: highly restricted fixated interests that are abnormal in intensity or focus
Criterion 3B	Apparently inflexible adherence to specific routines or rituals	Criterion B.2: excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
Criterion 3C	Stereotyped and repetitive motor mannerisms	Criterion B.1: stereotyped or repetitive speech, motor movements, or use of objects
Criterion 3D	A persistent preoccupation with parts of objects	(Criterion removed or possibly subsumed into criterion B.3)
New criterion		Criterion B.4: hyperreactivity or hyporeactivity to sensory input or unusual interest in sensory aspects of environment
Additional Criteria for <i>DSM-5</i>		
New criterion	Criterion C: symptoms must be present in early childhood (but may not fully manifest until social demands exceed limited capacities)	
New criterion	Criterion D: symptoms together limit and impair everyday functioning	

Abbreviation: *DSM-5*, *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition.

^a Adapted with permission from Bec Oakley.²⁸

did not account for adolescents who might not have demonstrated problems in social interactions until the social demands of teen life overwhelmed their ability to function. Supporters of the new *DSM-5* criteria also note that many of those who will lose the ASD diagnosis will meet social communication disorder criteria. Other potential benefits of the new criteria are that fewer clinical resources will be expended to type different disorders and that over time clinicians will be able to focus less attention on diagnostic typing and more on providing therapeutic services.

Not surprisingly, a number of individuals and groups have voiced genuine concern about the change. While people with Asperger syndrome will no longer be denied services reserved for people with ASD, those who see themselves as having Asperger syndrome and not autism may be given an inappropriate diagnosis, especially in adults for whom a developmental history may not be available.³⁷ Several studies published in the peer-reviewed literature in 2012 suggest that at least 12% and potentially as many as 40% of children

currently classified in one of the PDD subcategories will be reclassified or lose their diagnosis.^{33-36,38-42} Some of these studies indicate that the specificity is likely to improve using *DSM-5* criteria but that the sensitivity will potentially suffer, particularly for children with PDD not otherwise specified⁴³; however, these recent studies have various limitations, including using older data sets, applying older versions of *DSM-5* criteria, and using different types of diagnostic determinations (eg, clinician, parent report). Huerta et al⁴⁴ published a large-scale retrospective analysis of 4453 children with *DSM-IV* clinical PDD diagnoses and 690 with non-PDD diagnosis (eg, language disorder) and found that the proposed *DSM-5* criteria identified 91% of children with clinical *DSM-IV* PDD diagnoses and that the specificity of the *DSM-5* criteria was 0.63 as compared with 0.24 to 0.53 for *DSM-IV*. After publication of this study in October 2012, advocacy groups such as Autism Speaks viewed the *DSM-5* changes with cautious optimism and the Autism Society, the nation's largest grassroots autism organization, strongly advocates that individuals with ASD

should continue to access their existing services or maintain their waiting list positions if a diagnosis changes under application of the *DSM-5* criteria.

In light of this uncertainty, some have raised concerns that the loss of the subtypes will impact the validity of findings from ongoing research cohorts, a not-insignificant consideration given the explosion of autism research since the publication of *DSM-III*. Others have warned that changing diagnostic criteria in the middle of an “epidemic” will automatically undercut any sort of analysis because epidemiologists will now be comparing apples with oranges.⁴⁵

Critics have also maintained that the shift will have negative implications for clinical service delivery. This includes concerns that pivoting the diagnosis on social communication and repetitive behaviors may not have sufficient clinical utility because these factors seem to be weakly associated with clinical outcomes and response to treatment, which appear to be more closely related to cognitive and language abilities.^{37,46} For pediatricians, who are increasingly on the front lines of autism care, it is critical that the diagnostic process be clear and workable in a practice setting. The transition to *DSM-5* will have implications for differential diagnoses, require changes in terminology, and necessitate the development of new narratives to explain to parents what ASD encompasses.

Role of Pediatricians

In many states, the service delivery system is already fragmented and barely functional. Part C of the Individuals With Disabilities Education Act is responsible for the early identification and treatment of developmental problems in young children before age 3 years. Between age 3 years and high school graduation or age 21 years (whichever comes first), special education services are provided by public school districts. In adulthood, the services vary widely by state. At each of these levels, new eligibility determinations are made, resulting in periods of anxiety and vulnerability for parents. For example, in California, Part C of the Individuals With Disabilities Education Act is administered by a geographically based system of regional centers for persons with developmental disabilities that provide both diagnostic and therapeutic services to children younger than 3 years. At the third birthday, the regional centers then transition children to the school districts, which hold their own evaluations and eligibility determinations based on special education laws. After high school graduation or on the 22nd birthday, adults with autism are then transitioned back to the regional centers, which can provide services for the rest of the individual’s life. Many families experience significant stress and anxiety during the transition to adulthood, however, because the regional centers have limited available resources compared with school districts (eg, adolescents with autism may have been in a residential day program for 8 hours/day during high school but then get only 1-2 hours/day of programming in adulthood, leaving families responsible for providing structured activities on their own for their adult children with autism).

Many parents express concern that while it is difficult for schools to dismiss a diagnosis of autism out of hand, they fear that new ASD criteria will be an invitation for schools to deny services given current economic pressures and the expenses school districts are shouldering for special education services. In the end, *DSM-5*’s greater emphasis on more precise specification of functional capacity in core domains reflects a more scientifically valid approach to diagnosis and supports a conceptualization of the autism spectrum as a developmental disorder. Unfortunately, given how services are organized and financed, there will always be efforts to set thresholds of care regardless of how autism is categorized. If our ultimate goal is to enable all children to reach their health and developmental potential, then any changes in diagnostic classifications that change access to beneficial services (ie, those that work) for groups of children must be viewed with concern. Resolving the tension between promoting a more accurate set of diagnostic tools and ensuring that all children and families get the services they need is the challenge before us. From a parent’s perspective, the first goal of a diagnosis may be its clinical utility in charting a clear pathway to receive appropriate services that will increase independence and quality of life. However, these proposed changes also call to mind the longstanding ethical and policy dilemma of how limited resources should be used, ie, whether fewer children with more severe impairments should be the focus of care or whether resources should go toward helping more children with milder impairments who potentially stand a greater chance of benefiting from additional care.

Pediatricians and other primary care providers should be informed about these issues, especially given the number of questions that often arise about the diagnosis of autism in the primary care office setting. We should have a greater understanding of how *DSM-5* will impact both the diagnosis of autism and the subsequent eligibility of children for services. In the next few months to years, a period of transition will ensue during which most children currently receiving services for autism will not see a change in their eligibility; however, a group of children who qualified for services under *DSM-IV-TR* may lose their eligibility under the new diagnostic classifications.⁴⁷ Similarly, a small group of children who may not have qualified previously may now be eligible under *DSM-5*. Pediatricians will be important advocates for children and trusted sources of information for parents as they navigate this new, bewildering landscape.⁴⁸

The implementation of the new diagnostic classification of social communication disorder deserves close scrutiny as well. Given the criteria that ASD must be excluded for a child to be diagnosed as having social communication disorder, it is unclear whether the children in this category will have an entirely separate disorder or whether children with social communication disorder will end up being high-functioning children with ASD who are able to handle their social environments until they experience a significant challenge, such as entering high school or college. Also, it is unclear how these children will fare in the service environment, whether they will have eligibility only for speech therapy, whether speech-language pathologists will be able to handle the influx of patients this new diag-

nosis will uncover, and whether the speech-language pathologists will have the skills to be able to case manage this group of children and refer to other services as needed.

Finally, as parents and pediatricians are aware, autism is a lifelong condition. Children with autism become adolescents and adults with autism. However, in many settings, specialized resources for children with autism transitioning to adulthood are nonexistent. In addition to the loss of resources, young adults with autism often have new challenges they must overcome that require new levels of independence, decisions regarding higher education and/or vocational training, employment, health insurance, and health care. A recent comparative effectiveness report released by the Agency for Healthcare Research and Quality in August 2012 concluded that few studies have been conducted to assess treatment approaches for adolescents and young adults with ASD, and of those, most were of poor quality.⁴⁹ As is the case for other

chronic health conditions, transition from adolescent to adult care is fraught with a host of difficulties and requires special attention and major improvements.

Conclusions

As the service environment for autism is potentially disrupted by the new *DSM-5* criteria, parents, pediatricians, and all who provide care for this growing population of vulnerable children must adapt to this new reality and remain vigilant in advocating for optimal care. Child health care services researchers and others concerned with monitoring these changes and improving care will have an opportunity to assess the impact of the transition to *DSM-5* and to propose policy recommendations aimed at optimizing outcomes for all involved.

ARTICLE INFORMATION

Accepted for Publication: February 16, 2013.

Published Online: May 3, 2013.

doi:10.1001/jamapediatrics.2013.2188.

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Statistical analysis: Halfon.

Obtained funding: Halfon.

Administrative, technical, and material support: Halfon, Kuo.

Study supervision: Halfon.

Conflict of Interest Disclosures: None reported.

Additional Contributions: Elizabeth Karp, PhD, and Jennifer Frehn assisted in preparation of the manuscript.

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