

What Are the Stakes?

An Analysis of the Impact of the DSM-5 Draft Autism Criteria on Law, Policy and Service Provision

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Executive Summary

Over the last several months, considerable public attention has been paid to the topic of how the proposed DSM-5 draft criteria for Autism Spectrum Disorder might impact access to necessary services, supports, and accommodations for individuals currently diagnosed on the autism spectrum or who would qualify for a diagnosis under the DSM-IV. This brief is intended to analyze this question for individuals on the autism spectrum living in the United States. In particular, we identify and discuss the implications of three major shifts in the proposed DSM-5 criteria as compared to DSM-IV:

- a) the unification of three major autism spectrum diagnoses into a single diagnosis, called Autism Spectrum Disorder;
- b) the shift of some individuals receiving or who would have received a diagnosis of PDD-NOS under the DSM-IV to the proposed (non-autism) Social Communication Disorder diagnosis; and,
- c) the potential shift of some individuals currently receiving or who would have received a diagnosis of Asperger's or Autistic Disorder off the autism spectrum.

The DSM-5 has substantial implications for disability service provision, supports, and accommodations. The question of whether or not an individual has a psychiatric diagnosis recognized by the DSM is a highly relevant one in endeavoring to assess legal rights to non-discrimination, reasonable accommodation, special education services, income support, and more intensive forms of service provision supported through the Medicaid program.

Furthermore, the question of whether or not an individual has a diagnosis considered "on the autism spectrum" as compared to an unrelated diagnosis or one that explicitly precludes a diagnosis of ASD has become extremely important. This is largely the result of the codification of the autism spectrum as a recognized category with particular implications for law and service provision in a number of federal and state laws and regulations. In the brief below, we outline the implications of the DSM-5's shift in the definition of autism on four major areas of disability policy:

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- access to income support through the Supplemental Security Income program and the Social Security Disability Insurance programs;
- access to special education services through the Individuals with Disabilities Education Act (IDEA);
- access to non-discrimination protections and reasonable accommodation rights in employment, education, and places of public accommodation under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act; and,
- access to Medicaid-financed developmental disability services.

These four categories constitute the vast majority of public expenditures in the United States on disability services and the majority of legal protections available to people with disabilities in the workplace, in the K-12 school system, in higher education, and in society at large.¹ In each category, this brief summarizes the legal and policy details of the program under discussion and attempts to identify the likely implications of the DSM-5's outlined changes in the criteria for Autism Spectrum Disorder on eligibility, benefits, and access to services and legal rights. This brief is the first of two focusing on the DSM-5. Our second brief will outline ASAN's recommendations regarding the draft criteria and proposed severity scale.

Individuals with Disabilities Education Act

Passed in 1975 as the Education for All Handicapped Children Act, IDEA is the primary funding and legal mechanism governing the provision of special education services to students with disabilities in American public schools. IDEA provides a legal guarantee of a Free and Appropriate Public Education in the Least Restrictive Environment to all students with disabilities eligible for IDEA-mandated services. In addition to special education services, IDEA requires that students receive “related services” — such as speech pathology services, behavioral interventions, occupational therapy, and similar methodologies — in so far as such services enhance the student’s ability to access the general education curriculum. Not all children with disabilities are eligible for IDEA-mandated special education and related services. To meet eligibility under IDEA, students must a) possess a disability falling within one of IDEA’s 14 disability categories, of which autism is one, and b) require special education and related services as a result of their disability. Children with disabilities who are not deemed eligible for IDEA still receive non-discrimination and reasonable accommodation rights under Section 504 of the Rehabilitation Act, but are not entitled to special education and related services.

According to data from the US Department of Education’s Office of Special Education Programs Data Analysis System (DANS), 419,262 students from ages 3–21 currently receive IDEA-mandated services under the educational label of autism. This does not include students receiving services under IDEA’s Part C Early Intervention Services for children under age three. Furthermore, some students on the autism spectrum receive services under the “intellectual disability” or “multiple disabilities” eligibility category.

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Impact of DSM-5 Shifts on Students with Disabilities Receiving Services Under IDEA

IDEA defines autism as follows:

a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age 3 that adversely affects a child's educational performance. Other characteristics often associated with ASD are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected because the child has an emotional disturbance. [34 C.F.R. 300.8(c)(1)]

While this definition does not precisely track with either the DSM-IV or DSM-5 criteria for ASD, it is substantially easier for parents to establish eligibility under IDEA's "educational definition of autism" with a medical diagnosis of ASD. The DSM-5's impact will likely be mixed in this regard. Anecdotal evidence suggests that school districts are often unsure as to whether or not to consider a student with a diagnosis of Asperger's or PDD-NOS as qualifying for IDEA's autism category. Although legal precedent and regulation supports including Asperger's within IDEA's autism category, many families without access to high-quality resources and assistance during the eligibility determination process struggle to make school districts aware of this fact. As such, the DSM-5 shift to a single unified diagnosis of ASD will likely positively impact access to special education and related services under IDEA for those covered under the unified diagnosis.

For students re-classified into the new proposed diagnosis of Social Communication Disorder or who are otherwise ineligible for an ASD diagnosis under the DSM-5, the IDEA eligibility process may prove more challenging. Although it is not impossible to qualify for IDEA's autism definition without a medical diagnosis of ASD, it is substantially difficult. Eligibility for IDEA-funded services can be found through other IDEA disability categories, however given that analyses of DSM-5's sensitivity have found that individuals with higher IQ are more likely to lose access to the ASD diagnosis, the "intellectual disability" and "multiple disabilities" categories are likely not to apply.^{2,3,4} Some states and school districts utilize the potentially suitable "developmental delay" category, an option IDEA allows states and districts to adopt to provide special education and related services to children with unspecified developmental challenges. However, IDEA prohibits the use of "developmental delay" as an IDEA eligibility category for students above age 9.

Some possibility exists that children with a diagnosis of Social Communication Disorder may receive coverage under IDEA's Speech and Language Impairment category, whose definition is as follows, "a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, that adversely affects a child's educational performance [34 CFR §300.8(c)(11)]." However, the language of the statute is unclear as to whether or not issues relating to social pragmatics and primarily non-verbal communication challenges would qualify an individual for access to this category of eligibility for IDEA. Given tightening school district budgets, we believe that a more restrictive definition of this service category is most likely.

Thus, while a medical ASD diagnosis does not in and of itself ensure that a child can access services under IDEA, lack of a medical diagnosis of ASD can substantially

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reduce the likelihood of a student being eligible under the law. It is also worth noting that as it currently stands, the definition of Social Communication Disorder explicitly disallows the possibility that a child might also be diagnosed with ASD, implying that children within that category could be interpreted by school districts as being presumptively ineligible for the autism educational category within IDEA. It is unclear if children with a diagnosis of Social Communication Disorder would possess any rights to special education and related services under IDEA.

ADA/504 Accommodations

The Americans with Disabilities Act of 1990 is the primary civil rights law protecting Americans with disabilities against discrimination in the workplace, schools at both the K-12 and higher education levels, places of public accommodation, and state and local public programs. Section 504 of the Rehabilitation Act of 1973, the predecessor of the ADA, extends the same civil rights obligations to the federal government and all entities receiving federal funds. While the two laws apply in different settings, they possess the same essential structure, apply to the same group of people and offer the same protections. Together, they offer Americans with disabilities comprehensive civil rights protections, guaranteeing a right to non-discrimination as well as a right to reasonable accommodation so long as doing so does not constitute an “undue burden” on the employer, business, school, or other setting from which an accommodation is being requested. Both the ADA and Section 504 define a person with a disability as an individual with a substantial limitation of a major life activity.

For the ADA’s first eighteen years, its impact on children and adults on the autism spectrum was, while important, not as great as it could have been. Overly restrictive judicial interpretations of the definition of a “person with a disability” under the ADA made it difficult for individuals with less visible disabilities or who utilized various coping mechanisms or “mitigating measures” to compensate for their disability to qualify for the protections of the ADA. As a result, many individuals who had experienced discrimination found their ADA claims dismissed by the courts on the grounds that the law did not apply to them, regardless of whether or not they had experienced discrimination as a result of a diagnosis. Recognizing that this overly restrictive definition of disability was contrary to the original intent of the legislation, Congress responded by passing the Americans with Disabilities Act Amendments Act of 2008 (ADAAA). The ADAAA charged the judicial branch to interpret the definition of disability broadly, and without regards to any learned behaviors, adaptive coping mechanisms, medications, or other mitigating measures that an individual may be utilizing to control or compensate for their disability.

Although no specific disability is explicitly named within the ADA or ADAAA statute, the regulations implementing the ADAAA issued by the Employment Equal Opportunity Commission (EEOC) do explicitly mention autism as a diagnosis that should be presumed as qualifying a person with that diagnosis for the protections of the ADA. Discussing the impairments listed as qualifying for a presumption of coverage, the regulations state,

Given their inherent nature, these types of impairments will, as a factual matter, virtually always be found to impose a substantial limitation on a major life activity. Therefore, with respect to these types of impairments, the necessary individualized assessment should be particularly simple and

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straightforward... it should easily be concluded that the following types of impairments will, at a minimum, substantially limit the major life activities indicated: Deafness substantially limits hearing; blindness substantially limits seeing; an intellectual disability (formerly termed mental retardation) substantially limits brain function; partially or completely missing limbs or mobility impairments requiring the use of a wheelchair substantially limit musculoskeletal function; **autism substantially limits brain function**; cancer substantially limits normal cell growth; cerebral palsy substantially limits brain function; diabetes substantially limits endocrine function; epilepsy substantially limits neurological function...the types of impairments described in this section may substantially limit additional major life activities not explicitly listed above.⁵

Impact of DSM-5 Shifts on ADA/504 Protections

Although the ADA enhances the ability of all people with disabilities to claim civil rights protections under the ADA, the EEOC's explicit reference to autism within its regulations as a category that "virtually always" qualifies a person for civil rights protections is a significant asset to individuals seeking the protections of the ADA or Section 504. The explicit reference to autism makes it less likely that individuals on the autism spectrum seeking accommodations in employment or education will have to pursue litigation to determine their eligibility under the civil rights law.

The impact of the DSM-5's changes to the definition of Autism Spectrum Disorder will impact the ability of individuals to claim civil rights protections under the ADA and Section 504. Individuals who might previously have been diagnosed with a diagnosis on the autism spectrum who will now be covered by diagnoses of Social Communication Disorder or other non-ASD diagnoses will no longer have access to a presumption in favor of being covered as disabled for the purposes of non-discrimination and reasonable accommodation protections. We believe that this is likely to have the greatest marginal impact for children who might previously have qualified for accommodations in school under Section 504 but who did not meet the eligibility criteria for IDEA services and for adults who qualify for non-discrimination and reasonable accommodation protections in the workplace and in places of higher education but who do not qualify for Medicaid-reimbursable services from a state Intellectual and Developmental Disability agency.

Medicaid-Funded Developmental Disability Services

The Medicaid program is the primary financing mechanism for service provision to individuals with intellectual and developmental disabilities, including those on the autism spectrum. Medicaid is a state-federal partnership to provide health care for low-income individuals and people with disabilities. The structure of the Medicaid program's financing requires states to commit their own funds to cover between a quarter and one half of the costs of health care services for Medicaid-eligible populations, with the federal government picking up the rest of the cost. As a result of the availability of federal matching funds, states are more likely to fund service provision for populations eligible for Medicaid-reimbursable services than they are to fund similar services through their school systems, vocational rehabilitation agencies, or other entities that rely on state funds or less open-ended commitments of federal dollars.

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While Medicaid is known primarily as a program that pays for acute care services for low-income Americans, a significant percentage of the Medicaid budget supports long-term services and supports (LTSS) for people with disabilities and senior citizens. This funding stream is the primary mechanism through which most services for adults and many children with intellectual and developmental disabilities, including autism, are supported. Non-institutional LTSS are delivered primarily through the use of Medicaid Home and Community Based Services (HCBS) waivers. Medicaid HCBS waivers allow a state to serve children and adults with disabilities in their own homes or in small community settings. States apply to the federal government for authorization to create a Medicaid HCBS waiver, indicating the type and number of individuals the waiver will serve and the services incorporated within the waiver, such as habilitative services, attendant care, occupational therapy, speech pathology services, assistive technology, supported employment services, and a wide variety of other options.

Children and adults on the autism spectrum interact significantly with the Medicaid waiver program. Several states — among them Colorado, Indiana, Maryland, and Wisconsin — have Medicaid waivers specific to children on the autism spectrum.⁶ At least one state — Pennsylvania — has a Medicaid waiver specifically for adults on the autism spectrum. Individuals on the autism spectrum interact with both ASD-specific waivers and HCBS waivers designed for the broader Intellectual and Developmental Disability community. In determining eligibility for services, the specific ASD diagnosis an individual possesses is highly relevant. For example, Colorado and Indiana's waivers for children do not serve those with diagnoses of Asperger's or PDD-NOS.⁷ By contrast, Maryland and Wisconsin's children's waivers serve individuals with all categories of ASD.⁸

For individuals on the autism spectrum seeking to access services under general HCBS waivers, the question of diagnosis is also relevant. At least sixteen states include Asperger's within the definition of developmental disability utilized for HCBS waiver services.⁹ Within those states that do not mention Asperger's or other non-Autistic Disorder ASD diagnoses within their service eligibility definitions, individuals with a diagnosis of Asperger's or PDD-NOS who meet the functional eligibility criteria for I/DD service provision may be denied access to services. This is often justified by the scientifically unsupported argument that individuals with a diagnosis of Asperger's or PDD-NOS are qualitatively less impaired than individuals with a diagnosis of Autistic Disorder. In one recent Florida administrative law ruling, an Administrative Law judge upheld a state I/DD agency decision to deny individuals with a diagnosis of Asperger's eligibility for services, arguing, "The statute does not specifically address Asperger's, nor does a person diagnosed with Asperger's have the impairment in communication set forth in the statutory language."¹⁰

Impact of the DSM-5 on Individuals Receiving Medicaid-financed I/DD Services

The impact of the DSM-5's proposed shift to a unified diagnostic criteria for ASD is likely to improve access to service provision for adults seeking eligibility for Medicaid-financed long term services and supports who meet the functional eligibility criteria set forward by the state I/DD agency but who possess an ASD diagnosis not specifically listed within the service definition of that state. For individuals with diagnoses

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of PDD-NOS and Asperger's who experience significant degrees of functional impairment, the unified ASD diagnosis will mean a higher likelihood of arbitrary distinctions in service definitions being revised or abandoned. For example, the aforementioned administrative law ruling denying eligibility for I/DD services to individuals with a diagnosis of Asperger's specifically cited the upcoming DSM-5 changes, stating, "When DSM-5 becomes effective, neither the existing statute nor the Rule will clearly follow the new language concerning pervasive developmental disabilities, especially autism spectrum disorder. It may be necessary for a revision to both the statute and the Rule at that time."¹¹

There is reason for some concern that the shift of individuals to the Social Communication Disorder diagnosis or other non-ASD diagnoses may reduce access to service provision. For example, Medicaid HCBS waivers which are explicitly oriented around a diagnosis of ASD will not be available to fund service provision to individuals with non-ASD diagnoses. This may be of particular concern for children, given that individuals most at risk of losing access to an autism spectrum diagnosis via the DSM-5's changes (i.e: those with higher IQs, etc.) are more likely to interface with the Medicaid HCBS waiver program in childhood than adulthood.

Supplemental Security Income and Social Security Disability Insurance

Administered by the Social Security Administration (SSA), Supplemental Security Income and Social Security Disability Insurance constitute the primary means of income support for non-veteran, working-age people with disabilities who are not currently participating in the workforce or who are doing so to a very limited degree. The Social Security Disability Insurance program is a social insurance program, providing benefits to individuals who have paid into the system and met certain minimum work requirements. The Supplemental Security Income program possesses no past work or contribution requirements, but carries with it rigorous asset and income restrictions. Both programs carry with them health insurance components — SSI recipients receive access to Medicaid immediately after approval for cash benefits, while SSDI recipients receive access to Medicare 24 months after their approval for cash benefits. Both programs possess the same functional eligibility criteria, requiring an individual to prove disability through a five-step process (see below) and defining disability as the inability to engage in Substantial Gainful Activity (defined in 2010 as \$1,000/month in income from work) by reason of a medically determinable physical or mental impairment expected to last at least 12 months or result in death.¹² As of December 2009, approximately 6.5 million people with disabilities were receiving Supplemental Security Income. As of December 2010, nearly 9.7 million workers and dependents were receiving Social Security Disability Insurance.¹³

Despite SSA's definition of disability being defined by an individual's inability to work, it is widely recognized within the program and by Congress that individuals on SSDI and SSI can and should participate in the workforce. Beneficiaries do at times enter the workforce as a result of supports provided through their participation in or eligibility for the SSI and SSDI programs. The primary relevant example is the Medicaid Buy-In program, currently present in 42 states and the District of Columbia.¹⁴ This program was created in recognition that many individuals apply to the SSI and SSDI programs primarily in order to access the health insurance attached to each program. Medicaid

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is attractive to people with disabilities both by virtue of its broader scope of benefits and its availability to individuals whose pre-existing conditions would preclude them from accessing the individual health insurance market. While the latter problem may be fixed after the full implementation of the Affordable Care Act in 2014, the former will remain in place, given that private insurance typically will not cover necessary long-term services and supports or habilitative services for people with disabilities. The Medicaid Buy-In program allows working people with disabilities who meet the functional eligibility criteria of the SSI program to purchase access to Medicaid despite surpassing the work, income and asset restrictions of the SSI program.¹⁵

SSA assesses whether or not an applicant is disabled through a process consisting of the following five steps:¹⁶

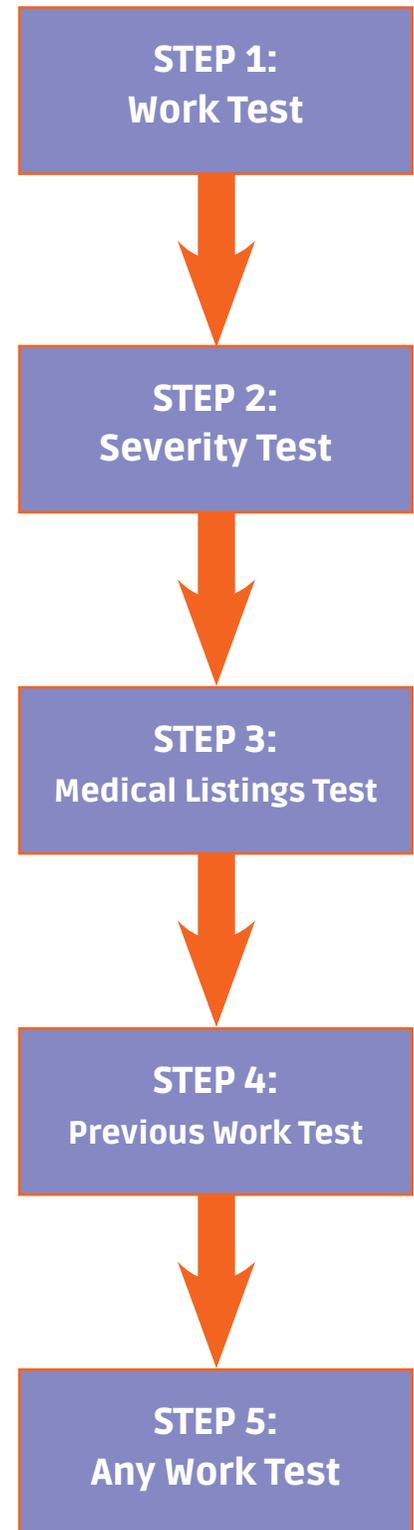
- **Step 1 • Work Test:** Is the applicant working and earning more than Substantial Gainful Activity (\$1,000/month for non-blind individuals)? If yes, the application is denied. **If no, move to Step 2.**
- **Step 2 • Severity Test:** Is the applicant’s condition severe enough to limit basic life activities for at least one year? If no, the application is denied. **If yes, move to Step 3.**
- **Step 3 • Medical Listings Test:** Does the applicant’s condition exist on SSA’s medical listings, or is it equal in severity to a condition found on the medical listings? If no, the application is denied. **If yes, move to Step 4.**
- **Step 4 • Previous Work Test:** Can the applicant do work he or she had done in the past? If yes, the application is denied. **If no, move to Step 5.**
- **Step 5 • Any Work Test:** Does the applicant’s condition prevent him or her from performing any other work that exists in the national economy, taking into account their age, education and work experience? If no, the application is denied. **If yes, the application is granted and benefits are awarded.**

To receive cash payments, an individual must meet all five of the steps outlined above, criteria that a significant percentage of adults on the autism spectrum may not meet as a result of their participation in the workforce, although many others will qualify. Many individuals on the autism spectrum, including those who currently qualify for the DSM-IV diagnoses of Asperger’s and PDD-NOS, are recipients of SSI and SSDI cash payments. To be eligible for the Medicaid Buy-In program, an individual must meet the eligibility criteria for the program without regards to work tests (Steps 1, 4 and 5). The vast majority of people on the autism spectrum would be able to meet the eligibility criteria for the Medicaid Buy In Program. Whether an applicant is attempting to access the cash payments components of the program or simply participate in the Medicaid Buy-In program to ensure access to health insurance, the SSA disability determination process is highly relevant to people on the autism spectrum.

Impact of DSM-5 Shifts on SSI/SSDI Applicants and Medicaid Buy In Program Participants

Step 3 of the process — requiring that an applicant show that their condition be listed on SSA’s medical listings or be equal in severity to one that is — is likely to be substantially influenced by the DSM-5 definition of Autism Spectrum Disorder. SSA’s Medical Listings include a specific category for “Autistic Disorder and other pervasive

Figure 1: Social Security Administration’s Disability Determination Process



developmental disorders.” Interestingly, both SSA’s definitions for childhood and adult applicants specify a slightly different process for individuals with Autistic Disorder as compared to individuals with other “pervasive developmental disorders,” implying that DSM-5’s shift to a unified ASD diagnosis may impact the assessment process. Whether that impact will be positive or negative is largely dependent on SSA’s interpretation of the DSM-5 criteria.

However, greater light can be shed on the impact of DSM-5’s potential shift of individuals to non-ASD diagnoses or outside the scope of the DSM, both with regards to the proposed creation of Social Communication Disorder and broader concerns raised about the sensitivity of DSM-5’s draft criteria for ASD. Although SSA allows applicants to meet Step 3 through the possession of a condition equal in severity to one found within the medical listings, those possessing a diagnosis enumerated within SSA’s medical listings are generally more likely to be approved for either cash benefits or access to public health insurance through the Medicaid Buy-In program. Applicants applying with a diagnosis of Social Communication Disorder or attempting to show evidence of equivalent impairment with another non-ASD diagnosis or without any diagnosis would be at a significant disadvantage compared to those with an ASD diagnosis. A shift in diagnostic practice leading to some individuals no longer qualifying for an ASD diagnosis would diminish access to both SSI and SSDI cash benefits and public health insurance through the Medicaid Buy In program.

It is likely that a greater impact may be felt by those attempting to access the Medicaid Buy-In as compared to those applying for both health insurance coverage and cash benefits, though the latter population may also be impacted to some degree. Due to the highly restrictive nature of the work tests (which those who only wish to access the Buy In do not need to pass) and the fact that beneficiary contributions cover a significant portion of the cost of the Medicaid Buy In, state agencies are often comparably lenient in assessing whether or not an applicant meeting SSA Medical Listings qualifies for participation in the Medicaid Buy In program. Applicants who do not meet SSA’s Medical Listings are likely to face a higher burden of proof.

Implications and Analysis

Our analysis suggests that DSM-5’s proposed shifts to the definition of the autism spectrum will have both positive and negative implications for children and adults seeking to access services, supports and accommodations. With respect to IDEA-mandated special education and related services, ID/DD service provision financed through the Medicaid HCBS waiver program, and possibly the income support and public health insurance offered through the SSI and SSDI programs, the DSM-5’s proposed unification of the major ASD diagnoses into a single diagnosis has the potential to improve access to services. The shift of individuals off the autism spectrum into other non-ASD diagnoses, such as the new Social Communication Disorder, or to no diagnosis at all, will likely diminish access to IDEA-mandated services, ADA/504 legal protections, the SSI and SSDI programs and their associated public health insurance, and Medicaid Home and Community Based Services waiver services. These concerns are serious and would have practical consequences to children and adults on the autism spectrum, their families and the professionals who serve them. At the same time, it is our belief that the potential problems we have outlined above are by no means inevitable and can be addressed through changes that nonetheless retain the basic structure proposed for the DSM-5.

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FIRST, it should be noted that the unification of Autistic Disorder, Asperger’s and PDD-NOS into a single diagnosis is a significant positive development that is not only consistent with the research literature but will also enhance the ability of people on the autism spectrum to access services, supports and accommodations across the lifespan. We urge the Work Group to retain the unified diagnostic category for Autism Spectrum Disorder.

SECOND, we urge the Work Group to consider changes to the diagnostic criteria to address concerns regarding sensitivity raised by the community and independent analyses of the DSM-5’s draft on ASD. Of particular relevance is number of criterion a person is required to meet under the Social Communication domain of the DSM-5’s definition of ASD. The current draft criteria requires individuals to meet three of three listed criteria, as compared to the two of four required under DSM-IV. Multiple analyses have suggested this may significantly impair sensitivity, and thus inadvertently push a significant number of individuals off of the autism spectrum. We are particularly concerned that individuals from historically underserved communities — such as racial and ethnic minorities, women and girls, and adolescents and adults — will be likely to lose access to diagnosis under this formulation. Particular emphasis should be given to this concern with regards to adolescents and adults, given the likelihood that individuals on the autism spectrum will develop various coping mechanisms and other learned behaviors which will help to “mask” symptoms of ASD. Most of the sensitivity analyses reviewed by the Work Group include few, if any, adolescents or adults within their sample size. As a result, we urge the Work Group to consider shifting the criteria required under the social communication domain of the ASD diagnosis from three of three to two of three. Failing this, we urge the Work Group to consider shifting this requirement specifically for individuals in adolescence or adulthood, indicating the likelihood of changing manifestations over the lifespan in the criteria itself.

THIRD, we urge the Work Group to consider the implications on service provision and legal rights of shifting individuals who at one point were or would have been diagnosed on the autism spectrum into the non-ASD Social Communication Disorder (SCD) diagnosis. As we have outlined above, the SCD diagnosis would provide none of the access to publicly funded service provision or legal rights under IDEA, the Americans with Disabilities Act or the SSI/SSDI income support programs and associated public health insurance. Despite this, SCD is likely to be a frequent misdiagnosis for ASD — a misdiagnosis whose implications would be stark and significant. SCD’s criteria also contains an explicit requirement that ASD be ruled out, making it likely that school districts would disallow the use of the autism educational category under IDEA to serve students with diagnoses of SCD. These issues can be addressed, however, by linking the SCD diagnosis to the broader autism spectrum, even as it retains a distinct diagnostic category. We urge the Work Group to consider re-naming Social Communication Disorder as ASD-Social Communication subtype (ASD-SC), ASD-Not Otherwise Specified (ASD-NOS) or another term which explicitly communicates to service provision and legal infrastructures the connection between the SCD diagnosis and the autism spectrum.

One of the most common maxims of the medical profession is, “First, do no harm.” We believe that this approach carries significant relevance to the DSM-5 process and urge its consideration as the Work Group reviews the implications of its forthcoming decisions. It is clear to us that the DSM-5 has the potential to be a significant improvement over its predecessor. We do not believe that a return to DSM-IV is possible or even desirable. At the same time, the dearth of information on potential impact of the DSM-

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5's changes on adolescents and adults combined with the concerning potential for loss of access to service, supports, and accommodations for those who will no longer have access to an autism spectrum diagnosis suggest that caution should be exercised in formulating DSM-5. Furthermore, the opportunity for more frequent revision of the DSM than has been present in previous iterations opens up the opportunity to gradually tweak and enhance the diagnostic criteria over time, further reinforcing the value of a cautious approach that works to safeguard the sensitivity of the ASD diagnosis. We believe that the Work Group has the ability to ensure that DSM-5 represents a significant positive step forward from its predecessor, and stand ready to assist in that process through the provision of information on the practical impact of the options before the committee.

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