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Lobbying Autism's Diagnostic Revision in the DSM-5

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Defining the boundaries of autism has always been a complex task, shaped by a wide variety of scientific, social, political, and economic factors. Those boundaries shape the lives of autistic people, influencing not only who gets diagnosed but often providing significant and important context to clinical decisions about service provision and "treatment" along with setting the stage for lifelong diagnostic and service disparities on the basis of gender, race, class, and age.

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Because autistic people are shaped by the diagnostic process, one of the Autistic Self Advocacy Network's priorities—as the leading organization run by and for autistic people—was to shape that process in return. We sought to do this with a variety of goals in mind: to address existing diagnostic disparities, improve access to service provision where diagnostic distinctions interfered, and to prevent a loss in access to legal protections, social legitimacy, and service provision by the narrowing of the diagnosis. While the Neurodevelopmental Disorders Workgroup charged with revising the autism diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [1]) consisted of researchers who conducted analyses and whose decisions received reviews from academic scholars [2], the process was still a political one, subject to efforts to influence the outcome. As a representative acknowledged, "This is not science – this is a committee" [3]. Furthermore, we maintain that the scientific and research processes are framed and mediated by larger social and political ones, and thus that dedicated advocacy and lobbying could influence the resulting diagnosis. In this, we were absolutely correct.

ASAN's advocacy work regarding the DSM-5 was led by the two authors, Ari Ne'eman (ASAN's co-founder and then President) and Dr. Steven K. Kapp (then a doctoral student at the University of California, Los Angeles and ASAN chapter Co-Director). While the organization was pursuing political and policy goals, we sought to ensure that ASAN's advocacy would be well-grounded in the research literature so as to maximize the likelihood of success and ensure the organization's credibility.

Ari led the lobbying effort and served as the primary point of contact with members of the DSM-5 Neurodevelopmental Disorders Workgroup. He also served as the primary expert on law and policy considerations in service provision. Steven led the research expertise side, serving as ASAN's technical expert on the research literature, providing comprehensive information on the existing autism research literature, and ensuring that the organization was capable of responding rapidly to questions or concerns raised by Workgroup members regarding the research literature.

Larger Context of Diagnostic Process

While the DSM had been revised previously, the current diagnostic process took on outsized public attention for a variety of reasons. Some of this was due to the simple fact that during the development of the DSM-IV [4], an organized community of autistic adults did not yet exist in significant numbers. The DSM-5 was the newly organized autistic community's first opportunity to weigh in on the criteria that governed who the medical community considered autistic.

But the DSM-5 process attracted additional attention for another reason: many in the autistic and autism communities were gravely concerned by rhetoric that autism was "over-diagnosed". Though the expansion of the diagnostic criteria in the DSM-IV had given large numbers of people access to legal protections, service provision, and a diagnosis and communal identity that helped them make sense of lifelong experiences of social isolation, odd interests, and other common autistic experiences, it had also sparked a backlash among some clinicians and members of the general public. Early media reports about the DSM-5 process suggested potential intent to narrow the diagnostic criteria [5]. These reports noted that the pathways to an autism spectrum diagnosis would shrink from 2027 to 11 possible "symptom" combinations [6] and that the committee had laid out an official goal to avoid false positives [5]. Further reports that the proposal would narrow the criteria significantly [7] sparked anxiety and deep worry among many. While the Workgroup did have another goal of improving identification in women and girls, racial and ethnic minorities, and adults—admitting the DSM-IV worked best for five-to-eight-year-old white boys [8]—further reports that the proposal would narrow the criteria significantly [7] sparked anxiety and deep worry among many that the proposal would leave many without access to the diagnosis who might benefit from it.

The committee's early proposal to combine the DSM-IV's main three autism diagnosis, Autistic Disorder, Asperger's Syndrome, and PDD-NOS, into a single unified autism diagnosis exacerbated these fears (though it was not the origin of them, e.g. Giles [9]). Many autistic people opposed the integration of the Asperger's diagnosis in particular into the larger autism spectrum.

However, this proposal was not intended as a measure to narrow the scope of the autism spectrum. Instead, it was rooted in significant research and clinical findings that the three autism diagnoses were applied inconsistently depending on the age and background of the person being diagnosed and the physician conducting the diagnosis [10]. Many individuals would receive multiple autism diagnoses across their lifespan, reflecting the fact that the three diagnoses had come to be used as a proxy for quality of outcome rather than being reflective of different phenotypes of autism. To quote one early commentary by the Neurodevelopmental Disorders Workgroup, "A single spectrum disorder [i.e., folding in Asperger Disorder and PDD-NOS] is a better reflection of the state of knowledge about pathology and clinical presentation; previously, the criteria were equivalent to trying to "cleave meatloaf at the joints" [11].

The proposal to unite the autism diagnoses paradoxically divided the autistic community, with individuals diagnosed with, and organizations based on, Asperger's leading the opposition. Michael John Carley, executive director of the Global and Regional Asperger Syndrome Partnership (GRASP, then led by individuals with the Asperger's diagnosis), represented the sense of superiority many of these critics felt over autistic people with higher support needs. "I personally am probably going to have a very hard time calling myself autistic," said Carley in an interview with National Public Radio, comparing the cultural perception of Asperger's as a diagnosis perceived as associated with major historical figures, like Edison and Einstein, to "somebody who might have to wear adult diapers and maybe a head-restraining device. This is very hard for us to swallow," [12]. While Carley [13] couched GRASP's leadership of the opposition to the DSM-5 in terms of concerns about diagnostic narrowing, he thus initially voiced his personal discomfort with the removal of a separate Asperger's diagnosis based on cultural identity. ASAN did not share this worldview. While we recognized that "autism" carried with it more stigmatized connotations than "Asperger's", we believed that such stigma could be changed. More importantly, there was no valid reason why it should be concentrated toward only one part of the autism spectrum until such time as that change could be accomplished. Though both Ari and Steven possessed Asperger's diagnoses, it was our belief that the best way to address stigma

was to confront it across the spectrum. Why did we deserve protection that other autistic people did not receive?

This was both reflective of our commitment to "cross-spectrum solidarity" and the essentially arbitrary process by which one individual might receive a particular diagnosis while another similar individual might receive another. Though "Aspie Supremacism" had been a longstanding problem in certain circles of the autistic community [14], ASAN had always insisted on a cross-spectrum perspective and consisted of a leadership and membership drawn from individuals who had received all three of the diagnoses (as well as some who had been unable to access a diagnosis due to various disparities).

We also believed that the three separate diagnoses contributed to service eligibility gaps, where laws, regulations, and policies by payers provided for eligibility for those with one diagnosis but not for others with comparable levels of impairment and need. In addition to their lack of clinical and research validity, ASAN had documented numerous instances where the three different diagnoses were used to limit access to services.

But concerns remained that, if the DSM-5 was implemented in an insufficiently precise fashion, some would be pushed out of the diagnosis. Early research on DSM-5 draft proposals suggested that the revision might lead to a narrowing in the availability of a diagnosis, pointing to early estimates that predicted a severe consolidation of as much as 54% overall (100% for those with Asperger's diagnoses in their sample; [15]). Asperger's had been crucial to the broadening of the eligibility for an autism diagnosis when the DSM-IV had come out, and many who had gained access to diagnostic legitimacy, legal protections and service provision feared their loss [9]. While ASAN supported the shift to a single unified diagnosis, we shared those concerns and engaged in advocacy in part to protect members of our community against the harms associated with the loss of a diagnosis by advocating for a broad formulation of a unified diagnostic criteria.

ASAN also sought to use the DSM-5 process to address other equity concerns, specifically race, gender, age, class, and geographic disparities in access to diagnosis. Significant racial disparities in access to diagnosis and service provision had been documented, with African-American and Hispanic children less likely to receive a diagnosis and, among those that

did, the diagnosis typically came later in life and for those individuals with more "severe"—obvious—autistic traits [16].

Similar gaps existed with respect to gender, though these disparities were often constructed as real biological facts rather than disparities in access to diagnosis. However, the autistic community had long maintained that, while the actual rate of autistic men and boys to autistic women and girls could not be definitively known, a significant percentage of that gap was attributable to gender bias and the resulting disparities. A growing body of research literature was coming to agree with us [16]. Furthermore, ASAN maintained that the DSM-IV criteria often made it difficult for autistic adults to receive a diagnosis, since we tended to develop various "masking" or "passing" skills as we grew up that hid the autistic traits we had had in childhood, even as the effort associated with passing still created cognitive demands and quality of life challenges not experienced by non-autistic persons [16].

Finally, we were deeply worried about proposals to write into the DSM-5 criteria for "recovery", reflective of a small number of studies that claimed to show autistic children losing their diagnosis in adulthood or adolescence. ASAN was skeptical of these findings, as a number of our members had been deemed "recovered" in childhood only to be re-diagnosed or find the autism diagnosis of continued relevance to them in adulthood. Even within the research literature supporting recovery, the vast majority who "lose" an autism diagnosis had it replaced with another diagnosis and continued to face significant challenges associated with the autism spectrum, suggesting that they were in fact simply learning how to "pass" and develop coping skills [17, 18]. ASAN was concerned that writing "recovery" parameters into the DSM-5 autism criteria would result in individuals losing their diagnosis and resulting access to services, legal protections, and communal identity when they develop meaningful coping mechanisms.

As a result, we advocated for the DSM-5 workgroup to avoid "recovery" criteria and to write into the DSM-5 autism diagnosis that individuals could be diagnosed based on present or past manifestations of autistic traits. Specifically, we sought to codify that learned behavior or other "mitigating measures" would not be held against an individual in seeking to access or retain a diagnosis. In this, we were borrowing a formulation that had been very successful in the Americans with Disabilities

Act Amendments Act of 2008, legislation ASAN had successfully advocated for ensuring that individuals would not lose the legal protections of the ADA if they successfully used "mitigating measures" to manage their disability.

Strategy and Tactics

In order to advance the priorities and protect against the concerns previously discussed, ASAN pursued a combination of social, political, and scientific strategies to "lobby" the DSM-5 process. Ultimately, our work was rooted in a simple reality, often obscured given the inscrutable nature of the process of making the DSM: it was written by people, and people can be communicated with, influenced, and convinced, even when they are autism researchers.

Early on, we made a judgment call that the autistic community, though possessed with an (in our opinion) indisputable moral claim to be represented in the DSM-5 process on an equal basis, lacked any material leverage with which to pressure the APA to include us on a formal basis or to accede to demands regarding modifications to the criteria. By this time, ASAN leadership had become experienced in running grassroots campaigns designed to secure autistic community priorities, even against opposition. We regularly conducted what would be referred to as a "pressure points" analysis in the leadership training we would later run for autistic college student organizers: identifying the levers through which advocacy could influence a target into complying with the autistic community's demands or making concessions toward those ends.

In the case of the APA, no material "pressure points" presented themselves. As such, even though ASAN was perceived as a more "militant" organization vis a vis the autism research and clinical worlds, Ari made a decision to operate a campaign based primarily on personality, persuasion, and evidence from the research literature. Our philosophy was always (and remains) using whatever tool is most effective for a particular job. Thus, a decision was made to cultivate relationships with individual workgroup members and the workgroup as a whole with the goal of convincing them

to advocate for our priorities and to provide advance copies of working drafts.

While Ari and Steven were the organization's primary leads on DSM-5 advocacy, others played critical roles. Scott Robertson, ASAN's co-founder and then a member of ASAN's board and a PhD candidate, also assisted the production of early documents sent to the workgroup and participated in early phone calls, as did Paula Durbin-Westby, an autistic activist on the board of ASAN and later to join the organization's staff. Zoe Gross, then an intern with ASAN and later to become the organization's Director of Operations, drafted critical background material provided to the workgroup on the challenges facing autistic women and autistic people of color in accessing a diagnosis and the resulting disparities these groups faced. She also provided illustrative examples regarding circumstances under which individuals might fall out of the boundaries of early drafts of the criteria, while still needing the support and recognition that an autism diagnosis could provide. Amanda Vivian, an autistic writer and creator of the Autistic Passing Project (http://autisticpassing.tumblr.com/), provided critical feedback on early drafts of ASAN feedback, among others.

While Steven provided research knowledge and scientific analysis to ASAN's work on influencing the DSM-5 continuously throughout the organization's advocacy, this intensified after he signed a contract in 2011. He led the writing of most memos and authored several independently. Topics included documenting the social abilities and social interest and empathy of autistic people, motor and movement issues, differential diagnosis, gender and race disparities, addressing potential misunderstandings of autistic activists and the neurodiversity movement, diagnostic practice, considerations for why the revision might "miss" autistic people, and so on. For specific and sensitive matters, he sometimes communicated directly with Members B or C (see below).

Communications with the Workgroup

In 2009, ASAN made contact with the DSM-5 Workgroup through one of its members, hereby referred to as Member A, whom Ari had corresponded with earlier regarding early intervention methodology. The two had earlier

found common ground over a shared critique of the excess rigidity of behaviorist interventions. Separately, Ari connected with the workgroup Chair at a meeting of the Interagency Autism Coordinating Committee (IACC) and, after Member A provided the Chair and Workgroup with a favorable impression of ASAN, Ari was invited to provide written and verbal feedback to the workgroup at several teleconferences and semi-annual in-person meetings in Washington DC hotel rooms. Ari also used the IACC as a vehicle for highlighting autistic community priorities and concerns regarding the DSM-5 during his two years as a public member of the committee (for more details on this from the perspective of an external observer at the IACC meetings, see Moore, pp. 169–198 [19]).

After an individual meeting with the Chair and phone calls with her and Member A, Ari met with the workgroup in person on the morning of April 8, 2010 (a meeting for which Steven provided significant research support). At this meeting, Ari stressed the importance of acknowledging "mitigating measures" and ensuring that individuals would not lose access to a diagnosis by virtue of their having learnt how to "pass" as non-autistic, a serious concern for many autistic adolescents and adults.

In addition, Ari stressed ASAN's opposition and concern regarding the severity scale, both in general and in its current formulation. ASAN was (and remains) worried that the introduction of a severity scale would be used by clinicians and service providers to set inappropriate "service goals" focusing on making autistic children and adults look and act "less autistic". We were particularly concerned by the fact that, at the time, drafts of the severity scale included references to "fixated interests", suggesting that clinicians and other professionals should try and redirect autistic children away from their passionate special interests, and to "repetitive motor movements", which many autistic people enjoy and which help us to self-regulate (and which we reclaim as *stimming*). Ari also indicated ASAN's concern with the draft criteria's emphasis on "social reciprocity", a vague concept whose most common clinical measures ASAN considered to be flawed.

This meeting was well-received by the workgroup, leading to a growing correspondence between ASAN and workgroup members both individually and collectively. ASAN soon made contact with Member B and Member C, who along with the Chair and Member A corresponded with Ari

and Steven to help inform the workgroup's deliberations. These Members did not necessarily agree with all of ASAN's recommendations—indeed, it was common for us to work with members on one set of priorities (i.e.: opposition to the severity scale, maintaining a sufficiently broad diagnosis, etc.) who disagreed with us on another set of priorities (i.e.: opposition to recovery criteria, etc.).

This made the establishment of relationships with as many members of the workgroup as possible a high priority. Ari, Steven, and others went to conferences in the US, Canada, and the UK—the home countries of workgroup members—where we knew that members would be present in order to make contact, establish a social relationship, and parlay that into communicating our recommendations and collecting intelligence on the current status of the draft criteria. At times, this resulted in drafts being provided to our team from individual workgroup members, to which ASAN provided specific and substantive comments (with academic references as appropriate). Other times, it simply resulted in the collection of useful observations on the attitudes of individual workgroup members toward our recommendations and their recollections of internal deliberations within the workgroup.

ASAN continued to correspond and meet with the DSM-5 workgroup members, though usually we were not invited to participate directly in workgroup calls and meetings, with a few exceptions. For example, ahead of the November 2011 meeting, ASAN developed a private memo making recommendations on the latest draft of the criteria, in particular urging a revision of the social communication domain from requiring 3 of 3 sub-criteria to qualify for a diagnosis to only requiring 2 of 3 criteria. (We also proposed an alternative recommendation of adding a fourth regarding language and speech issues, to require 3 of 4). This recommendation was not accepted, though others reflected in the memo were.

We also pushed for acknowledgment of motor movement issues and for strengthening of the language acknowledging that different contexts informed whether or not autistic traits would be visible. At the time, this language stated only that:

> symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities).

We recommended that the language be revised to read as follows:

> Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities, or because of compensatory or coping mechanisms developed over time).

The final criteria closely followed this formulation, reading:

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

The memo also urged the inclusion of greater material on adults, women and girls, racial and cultural minorities, socioeconomic status and other factors that influenced disparities in access to diagnosis, in the accompanying text, and provided the workgroup with illustrative examples for each. Finally, we urged the elimination of the severity scale and provided guidance for the accompanying text on differential diagnosis.

On the sidelines of the meeting, Ari met with Member B and Member C, communicating with each individually during breaks and the lunch period. This correspondence from Ari to Steven and Zoe, redacted to avoid disclosing the names of the workgroup members, provides some insight into the nature of these interactions:

> A few highlights, while they're fresh. Needless to say, none of this is for repetition or forwarding under any circumstances:
>
> – Met with [Member B] and [Member C] for 20 min., they report our document was well received by the Committee. I snuck a peek into their folders when I got there: every member of the ND Work Group had received a copy of our memo. [Member B]'s looked like it had been leafed through decently and they say they made use of it throughout the morning. Good job, team!:) Your hard work was not for naught.
> – They backed our severity scale concerns, said the dsm v apa folks requiring it of everyone, said they'd be willing to put language in accompanying text clarifying it not intended as proxy of treatment goals and outcomes, shouldn't be used as measure of service provision need. Pushed a bit more, they said they were open to dropping fixated interests

(and maybe rrbs?) from the scale and using a flexibility/ef measure along with social comm. instead. I pointed out that this might lead to more work occurring around self regulation.

– Focused mostly on accompanying text and severity, as they clarified that while the criteria MIGHT get opened up later, they've been instructed to leave it for now until field trial data comes back;

– Some willingness to elaborate on motor and language issues in accompanying text, said it was already there to some degree, they might expand on it;

– Our first discussion focused on how to capture adults in diagnosis who were hard to ID. They asked two starting questions: "what services did this population need and how would we suggest they guide a junior clinician who hasn't seen asd before as to how to identify these individuals?" Strongly emphasized that even those who don't require traditional types of service provision might still benefit from diagnosis to access ADA protections, reasonable accommodation and support groups. ([Member C] had tried to raise concern on "political motivations to access diagnosis" but this helped mitigate that concern or at least convince [Member C] that wasn't our motivation). Also pointed out that accurate diagnosis useful for clinicians providing treatment for co-occuring mh conditions like anxiety and depression.

We had a discussion on coping mechanisms (they referred to this as "scaffolding" and "masking") and the risk of individuals losing their diagnosis or not getting one in the first place. This was where we had more disagreement. [Member C] feels strongly that there are large numbers of people seeking an asd diagnosis who "just don't meet the criteria" as a way of escaping "legal, workplace or marital" problems. We pushed back here.

Discussed mechanisms of addressing masking in diagnostic process, I suggested greater weight to self report, [Member C] disagreed, citing again the supposed fakers trying to get asd diagnosis that doesn't fit. Respectfully disagreed, then reinforced that "do no harm" principle means that its better we capture a few folks that don't fit than risk pushing off folks who do. Not much agreement there.

Moved onto other potential ways for assessing what we both referred to as "cognitive impacts" for those who effectively "mask" behavioral traits. They were very interested in using anxiety and depression as possible proxies to catch those who are experiencing cognitive impacts due to masking. Pushed for inclusion in accompanying text.

– Steven, [Member C] disagrees strongly with your assessment re women and girls having distinct traits, feels there are "hundreds of studies that disagree with the few you cited". I pushed back here too, stated that while lit for bio based differences may be unclear, there is strong lit often outside of asd field for differences in manifestations between boys and girls due to upbringing, social context, etc. Pushed for acknowledgement in accompanying text.
– They agreed that a "subclinical" category on the severity scale was, on further consideration, a bad idea. They said it was intended to capture those who felt, "they had a condition, not a disorder" ([Member C] again). I stated that this is likely a corruption of Neurodiversity philosophy, these folks were trying to say "disability, not disease". We agreed - particularly [Member B] who was consistently more friendly - that there was real risk that a subclinical category could push folks "off the spectrum". I pointed out that it is unlikely those with a "subclinical severity" could access ADA and 504 protections.
– Whenever possible, I tried to move conversation to legal/policy impacts of their decisions, they don't understand law & policy and know we do, thus they're more likely to hear from us on those points. Made it very explicit throughout we had no intention of making "political/identity" arguments, only "practical/research and policy driven ones". They appreciated that."

As reflected in the above report, one of many written by Ari and Steven in their respective interactions with the workgroup or its individual members, ASAN had a complex relationship with the individuals we communicated with on the workgroup, some of whom shared most of our views while others agreed with us on only a few things. Some possessed views that we found extremely objectionable, requiring careful calibration in our communications with them to preserve the relationship while pushing back on viewpoints that had the potential to deeply harm our community if they were incorporated into the DSM-5 criteria.

Because of the power imbalance between the APA and the autistic community, and the tremendous impact that the DSM-5 could have on our community, we felt that an "inside game" was the most effective way we could promote change, thus our willingness to de-emphasize "political/identity" arguments. There is, of course, a certain irony here, in that

the "legal/policy impacts" of the DSM-5 are unquestionably political, but as those with decision-making authority in the process tended to present themselves as engaged in an apolitical endeavor, we adjusted our rhetoric accordingly to maximize effectiveness.

On January 31, 2012, ASAN issued a joint statement on the DSM-5 with the Autism Society of America, a parent-led group that we had an uneasy détente with, urging the "DSM-5 Neurodevelopmental Disorders Working Group to interpret the definition of autism spectrum disorder broadly, so as to ensure that all of those who can benefit from an ASD diagnosis have the ability to do so" [20]. This was made possible both by early efforts to build up a relationship between ASAN and what we then perceived as more moderate elements within the autism parent movement and the fact that concerns over the DSM-5 extended across traditional dividing lines of self-advocate and parent perspectives in autism. These concerns grew in response to a headlined *New York Times* report published days earlier about a preliminary study by the former chair of the DSM-IV workgroup, which warned that about 75% of people diagnosed with Asperger's and 85% of people diagnosed with PDD-NOS would no longer be eligible for an autism spectrum diagnosis [7]. While the Autism Society was a larger and better-funded organization, they had not built up significant internal technical expertise on the legal, policy, or research questions at issue within the DSM-5, requiring them to rely on our expertise as their concerns grew.

In June 2012, Ari and Steven released two policy briefs, timed to coincide with the final public comment period on the DSM-5, for which ASAN issued talking points to our grassroots in May [21]. The first, entitled "What Are the Stakes? An Analysis of the Impact of the DSM-5 Draft Autism Criteria on Law, Policy and Service Provision" provided comprehensive analysis of the implications of DSM-5 proposals on legal, policy, and service-provision systems. In this policy brief, we presented distinctive analysis that in special education, non-discrimination protections and rights to reasonable accommodations, developmental disability services, and income support, a shift to a single unified diagnosis would likely increase access to publicly funded service provision [22]. We also called attention to the fact that the proposed non-autism diagnosis of Social Communication Disorder, created by the workgroup in part to house

those who might be pushed off the autism spectrum, would likely be less useful in assisting individuals to gain access to services [22]. Later, a Workgroup member cited both policy briefs, referring to this first one as one of only three papers "of major importance" published on the then-pending criteria [23].

The second policy brief, entitled "ASD in DSM-5: What the Research Shows and Recommendations for Change" provided an academic evidence base for our concerns and specified our recommendations. The policy brief analyzed the draft criteria's likely impact on under-represented groups, placing particular emphasis on adults, women and girls, and racial and ethnic minority groups, and made another case for acknowledging motor/movement difficulties within the criteria. We also made several technical edits, and recommendations to address concerns of the revision pushing individuals off the autism spectrum (particularly due to the uniquely stringent social communication requirement). For example, we recommended attaching the Social Communication Disorder diagnosis to the autism spectrum, "possibly by renaming it as ASD-Not Elsewhere Classified or ASD-Social Communication subtype", increasing its utility as a means of accessing services. The policy brief was deeply grounded in the research literature, with 216 different citations of a wide array of peer-reviewed autism research studies [16]. A Workgroup member cited it within a study applying the DSM-5 criteria to adults, agreeing based on their own research that the minimum requirements for meeting criteria could be relaxed to correctly identify more people as autistic without significantly adding false positives [24].

Our final engagement with the WorkGroup took place at an in-person meeting in late 2012, when Ari was invited to attend the last meeting of the DSM-5 Neurodevelopmental Disorders WorkGroup before the criteria were finalized. There, he reiterated our concerns regarding sensitivity and made a final impassioned plea to consider loosening the social communication domain or linking Social Communication Disorder to the spectrum. Michael John Carley of GRASP also received an opportunity to comment via phone, reiterating GRASP's opposition to the loss of the separate Asperger's diagnosis. Though we did not succeed in achieving all of our goals, we nonetheless substantially influenced the final diagnostic criteria and the accompanying text.

Outcomes and Implications

ASAN's effort to lobby the DSM-5 is historically significant in that it represents the first successful effort of the autistic community—and as far as we are aware, any disability community—to successfully influence the modification of their own diagnostic criteria. While communities have successfully advocated to eliminate a diagnosis from the DSM (i.e.: homosexuality) or to incorporate one, we are aware of no prior example of successful advocacy to refine and improve diagnostic criteria from the community subject to it.

Having said that, we were only partially successful at achieving our advocacy objectives, owing in large part to the lack of any formal recognition of the value of autistic input in the development of the criteria earlier in the process. While the Neurodevelopmental Disorders Workgroup ultimately chose to acknowledge Ari as a formal advisor to the DSM-5, it did so only after the criteria had been finalized. Even then, they did not inform us ahead of the fact that this was planned. (Had they done so we would have pushed to formally acknowledge Steven's role as well.) Nevertheless, the Workgroup Chair singled ASAN out for praise before international researchers [25], as did another member before the autism community, thanking us for our "steadfastness in tracking diagnostic criteria", which he said had been "extraordinarily helpful" [26].

And yet, the vast majority of workgroup meetings took place without autistic input, with only a small number of direct contacts between ASAN personnel and the workgroup as a whole (as distinct from the successful cultivation of some individual members). Autistic input in the DSM-5 ultimately took the form of an intelligence operation, requiring the licit and illicit cultivation of assets to collect partial information on potential revisions and inform formal communications regarding requested changes. It would have been far preferable for the autistic community to have received a direct and acknowledged seat at the table.

Perhaps because of this lack of formal recognition, only some of ASAN's goals were accepted into the DSM-5. The unique diagnostic needs of adults (including that allowing self-report may strengthen the assessment process, particularly for those who lack relatives with access to their clinical history), women and girls, and racial and ethnic minority groups were

incorporated into the accompanying text, though not in as much detail as we had pushed for.

No "recovery" criteria were incorporated into the diagnosis, and the severity scale includes no reference to "subclinical" autism, a category that would have made it substantially harder for those included within it to access legal protections and service provision. Both are likely the result of our efforts. In addition, modifications were made to the severity scale that mitigated its potential harms, though it was still incorporated against our recommendation and even the Workgroup's objection [26].

The APA required a severity scale as part of all diagnoses in the DSM-5, yet ASAN's influence led to several notable concessions regarding it and related text. The Workgroup reframed the scale as about need for support because individuals might function well *because* of support and we did not want that support taken away. As Workgroup Chair Sue said, "I think the example that was given to us [by Ari], if you need a crutch to be able to walk, but you walk perfectly fine with that crutch, you don't want to, then, say you don't need that crutch anymore" (p. 198) [19]. Similarly, after rejecting our call to eliminate the scale altogether due to APA's insistence, the Workgroup adopted ASAN's backup recommendation to try to defang the scale by prohibiting its use for services: the accompanying text to the DSM-5 states that "the descriptive severity categories should not be used to determine eligibility for and provision of services" and that "these can only be developed at an individual level and through discussion of personal priorities and targets" (p. 51) [1]. Furthermore, the emphasis on inflexibility or executive functioning in, and removal of "fixated interests" from, the restrictive and repetitive behaviors domain of the scale, result from ASAN's involvement. In parallel, the accompanying text states, "Special interests may be a source of pleasure and motivation and provide avenues for education and employment" (p. 54) [1].

In other respects too, the final text reflected ASAN's argument that autistic people's manifestations of their autism and functioning vary too much to be applied systematically to service provision and clinical practice. The main text's clarification that the examples given "are illustrative, not exhaustive" closely followed ASAN's recommendation [16]. The Workgroup adopted our recommendation to loosen the requirement for social communication deficits "across contexts" to "in multiple contexts" in the

main text, and limited the emphasis on relationship deficits to those with *peers*. Similarly, it noted the context-dependent nature of autistic people's functioning multiple times in the accompanying text. Through our comments on confidential drafts of the diagnostic text, ASAN successfully encouraged language recommending that multiple sources of information be used together in assessment to identify behaviors that do not always present clinically, such as direct observation and interaction, interview on history, and other reports, which can dramatically increase the likelihood of identifying autism [27, 28]. As concessions to our input, the Workgroup added language noting uneven skills and a common gap between IQ and lower adaptive behavior—which challenges the notion of "high-functioning" autism. It likewise added advice that autistics with limited language may show strengths on nonverbal, untimed cognitive tests—which challenges "low-functioning" or "severe" autism tropes.

Perhaps most importantly, the inclusion of ASAN's requested language allowing diagnosis "currently or by history" as well as acknowledging that "symptoms…may be masked by learned strategies in later life" (described further as effortful and taxing in the accompanying text) offers meaningful opportunities for autistic adults to be diagnosed at greater rates than they have been previously. The inclusion of this language likely mitigated some of the anticipated narrowing of the diagnosis and opened up opportunities to address diagnostic disparities, especially on the basis of age. Other quieter influences more literally ensured access to diagnosis, such as retaining the ability to diagnose OCD alongside autism (we provided ample studies differentiating them).

Nonetheless, evidence does suggest that some narrowing did take place. Studies applied prospectively that compare DSM-IV with DSM-5 criteria reported that the latest revision narrowed eligibility for an autism spectrum diagnosis by between 4% [29] and more than 10% among children, with higher proportions missed for children with previous Asperger's (20%) and especially PDD-NOS (75%) diagnoses [30]. The DSM-5 particularly missed girls, older children, and children with subtler autistic behaviors [30]. Still, preliminary evidence does suggest DSM-5 increases access to services (e.g. in special education) for those diagnosed [29], and likely the revision would have missed many more people were it not for ASAN's efforts.

Had our recommendation to require only two of three criteria in the social communication domain been accepted, this narrowing would likely not have taken place, or would have not taken place to the same degree. The DSM-5 will likely "miss" more people as individuals increasingly get assessed for the autism spectrum for the first time. Those who already had a diagnosis have a limited amount of protection, as the Workgroup ceded to pressure by seeking to soften the transition to the new system through the following language: "Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder" (p. 51) [1].

Emerging evidence on the implementation of DSM-5 confirms our concern about the severity scale. It is our experience that when categories of "severity" are provided they inevitably are used as mechanisms for ascertaining service eligibility or service/treatment goals. Indeed, the National Insurance Disability Scheme in Australia, enacted since the completion of the DSM-5, interprets the lowest support level ("Requiring support") as usually disqualifying autistic people from eligibility for services (https://www.ndis.gov.au/). Fortunately, academic studies suggest the "need for support" framing has shifted some attention toward disability (low adaptive functioning) as well as non-specific disability characteristics sometimes associated with autism such as low cognitive ability [31, 32], without a consistent relationship between these developmental domains and core autism "symptoms" [33].

This is a good thing, as we have always believed that the focus of service provision should be on improving adaptive functioning and other person-centered goals, rather than trying to "correct" or "cure" autistic traits. If the scale is being used as a guide for service or treatment goals, then it is particularly fortunate that ASAN secured the removal of "fixated interests" and "repetitive motor movements" as measures within the severity scale, given the importance of "special interests" and "stimming" to many autistic people and the clear autistic preference for services oriented toward improving happiness and quality of life rather than the enforced imitation of "typical" behavior and appearance.

In contrast, the introduction of the social communication disorder (SCD) diagnosis appears less damaging because it is rarely utilized. As

a major communication scholar and autism researcher put it, "Entry into the DSM…has not changed anything: There are no new assessment tools, no clear diagnostic criteria, no stronger evidence for the existence of the condition and no innovative, effective interventions" [34]. It has attracted little interest in practice: "Whatever the reason, most expert clinicians do not find the new diagnosis necessary or useful", she added. Nor do researchers, as "more than 10,000 papers have the term 'autism' in the title" compared with "just 10 papers on 'social communication disorder'".

Neurodiversity activists deserve some credit for the dearth of diagnoses of SCD, as we have helped to improve attitudes toward autism such that the SCD diagnosis rarely gets assigned to reduce stigma (as the Asperger's diagnosis once was used). This apparently almost unused diagnosis further validates ASAN's approach to not let the supposedly greater stigma of "autism" interfere with a unified spectrum diagnosis. The relatively low utilization of the diagnosis is positive, given our longstanding concern that a SCD diagnosis would open up access to significantly less support than an autism diagnosis does. Nonetheless, we continue to believe that the social communication domain of the autism criteria should be loosened. Indeed, a large study using major databases found that more than four times as many autistic children failed to meet the social communication domain requirement only (more than 6.2%) as compared to the restricted and repetitive behavior domain (less than 1.5%; Huerta et al. [35]). We activists emphasize that social communication always results from broad factors within and between people [36, 37].

These kinds of "practical" knowledge of the other side of the service system support our later recommendation that future iterations of the DSM should formally include autistic input on the workgroup.

Moving forward, we make the following recommendations for future consideration:

1. **Acknowledge the DSM as a Political Process *and* a Scientific One**: While ASAN was careful to root our advocacy regarding the DSM in scientific rather than political language, we always understood the process as both a political and a scientific one. We mean this in a non-pejorative way, simply acknowledging the reality that any effort to articulate a diagnostic criteria will have distributive consequences in

terms of public resources and social consequences in terms of identity. In the future, we urge others to acknowledge the political dimension of the DSM, not with the intent of denigrating the process, but to allow open consideration of factors that influence those writing the criteria and to acknowledge the consequences of those criteria on those that are subject to it. Similarly, we urge other communities to learn from our example in exploring how they too can play a larger role in influencing their diagnoses, while leveraging scientific knowledge.

2. **Provide for Autistic Representation in Future Revisions**: The next iteration of the DSM should provide an opportunity for autistic voices to be represented as full and equal partners within the workgroup developing the criteria. This reflects both the considerable sophistication of the autistic advocacy community in understanding and engaging with the research literature and the moral claim for representation, consistent with the longstanding disability rights principle of "Nothing About Us, Without Us!" Such representation may take multiple forms, both involving organized autistic-run groups like ASAN, and the growing number of openly autistic researchers with expertise in autism, an increasingly common phenomenon.

3. **Abandon the new Severity Scale and the SCD Diagnosis**: The political dimension was not lost on all of the Workgroup—one member acknowledged that the group introduced the SCD diagnosis for "political and health reasons…DSM-5 was not a scientific process…the empirical evidence is *not* in support of social pragmatic disorder" (Lord in [38]. Furthermore, the inconsistent relationship between the degree of core autistic traits, intellectual ability, and adaptive functioning, as well as lack of consensus on how to measure "severity" in autism [39], suggest the need to abandon the severity scale. If they are retained, further research is also needed on the service and clinical implications of both the severity scale and the frequency of the SCD diagnosis. It is our belief that such research would ultimately validate our view that they should be eliminated.

4. **Prioritize Research into the Distributive Implications of the DSM-5 across Groups**: Preliminary evidence suggests that much work remains to close racial and gender disparities in access to diagnosis, and that class, age and geography remain as factors in who gets access

to a diagnosis and who does not [29]. Research should be conducted to ascertain if DSM-5 has led to a narrowing or expansion of the autism diagnosis, identifying which groups have been impacted in which way, and understanding the particular aspects of the new criteria that are contributing to that outcome. Particular priority should be given to understanding the impact of the criteria on adults and autistic people with less obvious traits.

5. **Allow for Near-Term Further Revisions**: As new information becomes available on the implications of the DSM-5 criteria, the APA should acknowledge the need for a DSM-5.1, 5.2, 5.3, etc. before the DSM-6 process begins. Because so much information used by clinicians is now provided online rather than in textbooks, APA has an unprecedented opportunity to deliver revisions to the criteria on a faster timetable than in the past, while still acknowledging the importance of stability and careful deliberation. This revision process should include autistic voices as full partners and prioritize ensuring that autistic people are not adversely impacted by loss of access to the diagnosis and resulting services and legal protections.

The DSM is not provided on stone tablets brought down from a mountain—it is a document, written by people, and as such can be influenced using creativity, evidence, and strategic argument. Historically, critiques by disabled people of the DSM have often been critiques of psychiatry itself, either in general or in terms of its specific applicability to particular groups. This has not lent itself to collaboration between clinicians and disabled activists, since the latter tend to see the DSM itself as illegitimate. Some associated with the "anti-psychiatry" movement even reject the idea that diagnoses represent actual underlying neurological differences from the norm as opposed to purely responses to trauma.

ASAN's perspective is different and is instead rooted in the idea of "neurodiversity", which challenges the "medical model" that assumes that the goal of service provision or "treatment" is to restore autistic people to

"normalcy" or, as Lovaas put it, indistinguishability from peers [40]. While we reject the idea that interventions should stress "indistinguishability" and often challenge the idea of exclusive medical authority, we do not reject the utility of the autism diagnosis itself or the well-documented reality that it constitutes a real divergence from "typical" neurology.

In short, we largely agree with psychiatry as to what autism is (a difference of neurology) and feel that scientific research should play a key role in defining the diagnosis. Nonetheless, we believe that identification of autism should transition to a non-pathological system that allows inclusion of evidence-based neutral differences and strengths, recognizing that autistic traits can be strengths, challenges, or neutral depending on context (and are often deeply valued by autistic people ourselves; Russell et al. [41]). And while we agree with psychiatry that autism emerges from neurological differences, we disagree with many assessments of how autistic people should be treated—and wish to call attention to the social, legal, and political context in which research and diagnosis take place.

The neurodiversity movement, as we understand it, is in creative tension with mainstream psychiatry, not in opposition [42]. This is useful in that we are able to articulate an important critique as to how autistic people are treated while agreeing that the autism diagnosis delivers value and should be maintained. This is the theoretical framework that allowed our collaborative approach to DSM-5 advocacy to be as successful as it was.

To complete that success, however, psychiatry must acknowledge the autistic community (and other similar communities) as an equal, not as a junior partner. Future iterations of the DSM should include autistic people within the process in an explicit and acknowledged fashion, sparing us and them the aggravations, inefficiencies, and hypocrisies inherent in our needing to launch complex influence operations to have our views represented. It is our sincere hope that as the worlds of autism research and clinical practice continue to mature, such a partnership will take form.

As always, Nothing About Us, Without Us!

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