

More on the DSM-V changes and what we need to do and why it is so important that we stop this/ From GRASP Founder

(sent from COPAA list - 1/22/12)

Dear all:

Thank you for the calls and the emails. We are having a positive effect, and with 10 months before the final version of the new DSM is due, we have a chance of reversing the Committee's intentions of significantly reducing the numbers of those who would qualify for a diagnosis. Please keep it up starting Monday morning.

Once again, [the New York Times is speculating](#) that the new criteria would qualify only 76% of those currently diagnosed with classic autism, 24% of those currently diagnosed with Asperger's, and 16% of those currently diagnosed with PDD-NOS. This means that:

- Children who do not qualify for a diagnosis under the new revisions will almost certainly be denied special education funding by their cities and states (after all, what school board will spend money on a child with no officially recognized learning challenge?)
- Many adults on SSI, SSDI, or Disability who barely meet the criteria for these services may not have those services (and health coverage) anymore.
- We risk a possible return to the days of 1993 and prior where negative interpretations of behavioral differences were rather status quo.

The motivations behind these mind-boggling changes, are very much unclear to us. While the autism world in our current void of information is speculating a multitude of possibilities—the most dramatic being improper influence of insurance companies—we would urge people to continue pressing the DSM-V committee with the idea that the current committee members have experience only with the more-challenged end of the spectrum. None have any real experience with the end of the spectrum whose challenges are less physically-visible.

In addition to your talking points, and if you believe that the motivations are in any way fiscal, we urge you to remind the committee of how, in the big picture, the DSM-IV (which expanded spectrum diagnoses) saved us money. When you think of (though cannot estimate) the reduction in anxiety, anger, and depression, that was caused by legions of people finally understanding who they were—that they were wired differently, not rude . . . argue the mind-boggling cost of returning to those levels of anxiety, anger, and depression. *(I am inserting my comment here- this part is not from the letter forwarded from Mr. Carley but I feel it is crucial that we continue to stress this as well-- we cannot underestimate the long term savings due to appropriate supports and services that were provided prior to adulthood that will reduce the need for extensive supports and services throughout the lifespan. If appropriate supports and services are provided prior to adulthood, more individuals are able to achieve independent living skills with fewer supports in place. Without these appropriate supports and services, more individuals will end up reliant upon extensive social services throughout their lifespan, but they likely will not qualify*

under these new guidelines.-- What do they plan to do about all the adults they will be cutting off now because they no longer will qualify for services- who is going to provide assistance and what do we do with a soon to be burgeoning population that has no supports in place- the societal cost will be catastrophic-- Insurance companies in their infinite wisdom will ultimately be sticking social services and families with costs that will literally and utterly bankrupt the system which will end up hurting us all).

Responses

While in our last update, we conveyed the APA's statement that they were not taking comments at the present time, committee members and other organizations are now starting to respond through either internal or external media. In general you should feel you have every right to respond to these responses. The two most frequently seen tones (followed by our suggestions) are follows:

1. "Well, yes, your child may not qualify for specialized education under the new criteria, but please bear with us. Our hope is that this will improve services for all." They do not go on to explain how this is possible.

1R. Our no-brainer suggestion is to point out how senseless this response is. If they're admitting that fewer will qualify, how does this improve chances of "improving services for all." If your anger is getting the better of you, politely state that their response makes things worse because you feel your intelligence is being insulted.

2. These events are reviving the dormant "competition of suffering." Many people (who likely have some connection to a significantly-challenged fellow spectrumite) across the country in facebook posts, tweets...etc. are proclaiming "Good! Autism needs to be less confusing. These (AS or PDD-NOS) people never should have been brought in to the spectrum equation."

2R. Do not meet their hate with hate. The self-incriminating and emotionally-unhealthy nature of these attacks is the product of their being unable to grasp the complexity of the spectrum, or they are simply overwhelmed and underserved when compared with their needs. Yes, they may simply be bad people, but we won't know that (and we have bad people too). As they invalidate the experiences of others, do not match their ugliness. If you must respond, something appropriate would be akin to "I find it so sad that you would deny help to someone else simply because you still need help (embellish with detail that perhaps pertains to your experiences)." Show them, do not tell them, how ill they were in the moment of writing.

Once again [our facebook page](#) is the best place to dig up prior developments. And once again, keep the calls coming. Call the American Psychiatric Association at [703.907.7300](tel:703.907.7300). They will ask you not to call, but please keep calling. In addition, please email them at dsm5@psych.org and apa@psych.org (apologies: we misspelled the latter in our last correspondence).

Look for a survey from us soon too.

With massive thanks, we are

Yours, y'all,

Michael John Carley
Executive Director

GRASP

The Global and Regional Asperger Syndrome Partnership, Inc.

666 Broadway, Suite 825

New York, NY 10012

p + f = [1.888.474.7277](tel:18884747277)

www.grasp.org