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How Will the New Definition of Autism Affect Those In Need of Services?

On January 20th, 2012, the American Psychiatric Association (APA) proposed that the diagnosis of autism in the new fifth revision of the Diagnostics Statistical Manual (DSM-5) would undergo a significant change. Currently, the standards separate the autism spectrum into different disorders. They include Autism, Asperger Syndrome, Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The APA believes that the previous version of the DSM created confusion and misdiagnosis by separating similar disorders under an overly broad spectrum. Simultaneously, the labels are too narrow because they are black and white; each one is a simple yes or no answer to whether a person has a certain disorder. The APA now proposes a single label that encompasses the previous four disorders into a continuous range of severity called *Autism Spectrum Disorder* (ASD). Now, doctors would classify autistic patients from mild to severe, but the criteria for ASD is narrower compared to previous definitions of autistic disorders. In DSM-4, autism symptoms were organized into three separate categories and a minimum of six out of twelve symptoms across the categories were required for a diagnosis. The proposed standards in DSM-5 cut the criteria down to seven symptoms and require all of them to be met in order for an ASD classification.

The APA's press release expressed enthusiasm for the changes. Early on it said, "Dr. James Scully, Medical Director of the American Psychiatric Association said, 'The proposed criteria will lead to more accurate diagnosis and will help physicians and therapists design better treatment interventions for children who suffer from autism spectrum disorder.' " Later in the release, it also stated, "This change will help clinicians more accurately diagnose people with relevant symptoms and behaviors by recognizing the differences from person to person, rather than providing general labels that tend not to be consistently applied across different clinics and centers."

However, many parents fear the new changes are too narrow and could potentially exclude their

children from services. In Massachusetts this is especially a concern due to last year's passage of a bill called "An Act Relevant to Insurance Coverage for Autism" (ARICA). This bill requires insurance providers in Massachusetts to provide coverage for disorders in the current autism spectrum. Previously insurance providers had been dropping or refusing coverage for autistic children and adults, but ARICA now prevents such actions. In the last decade, Massachusetts has also been progressive by providing many services for disorders of the autism spectrum. Massachusetts' Departments of Education and the Department of Developmental Services in particular provide essential services to autistic children. With the new definition some parents and activists fear their children and family will be denied services and insurance they worked extremely hard to obtain.

CNN Political Commentator Nancy Grace remarked on her show, "This new definition will dramatically reduce the number of people clinically diagnosed...parents and doctors are in fear that funding for all these treatments will be cut." In a New York Times article entitled "New Definition of Autism Will Exclude Many, Study Suggests," a parent with a daughter diagnosed with Aspergers expressed fear over losing benefits. "'I'm very concerned about the change in diagnosis, because I wonder if my daughter would even qualify,' said Mary Meyer of Ramsey, N.J. A diagnosis of Asperger syndrome was crucial to helping her daughter, who is 37, gain access to services that have helped tremendously. 'She's on disability, which is partly based on the Aspergers; and I'm hoping to get her into supportive housing, which also depends on her diagnosis.'"

On the other hand, a narrower diagnosis tied directly to a spectrum could benefit people on the higher end. Some people barely meet the current criteria, but still receive the diagnosis of being autistic. The currently broad criteria lumps high functioning, mostly normal people, in with persons who have severe social and learning deficiencies. Is it really ethical to label ordinary people with autism? In an interview with Fox 25 News Boston, Dr. Janice Ware, a pediatric psychologist from the Children's Hospital in Boston expressed, "They are cleaner diagnoses, which will give us better guidelines on how to treat the children. The previous diagnoses did leave room for including children

who had some atypical features, but really did not rise to the full criteria to fit the diagnosis.”

Like the spectrum itself, the entire situation is complicated and does not have easy answers. Everybody I personally spoke to regarding this issue had mixed feelings, and even uncertainty regarding how autism treatment and research would be effected in Massachusetts and elsewhere. Mary Loughlin, an advocate and occupational therapist with two adult males with autism told me, “For some individuals presently now on the higher end of the spectrum, it may be a positive to no longer be labeled with a psychiatric diagnosis with little to no benefit. But for other individuals who need to be identified in order to obtain needed benefits through school, insurance, state agencies and services, adult work, etc., I fear they may fall through the cracks of the system.” She went on to explain to me how she believed there was a possible connection to the rapid growth of autism diagnosis in Massachusetts at the turn of the century, and a change in the definition of learning disabilities by the Massachusetts Department of Education. Around 2001, 30,000 children were excluded from the learning disabilities programs in Massachusetts public schools. Since children still needed benefits, she believes many parents had their children diagnosed with Aspergers and/or ADHD in order to continue receiving help and services from public schools. If Mary Loughlin is right, then it means history could potentially repeat itself. While scientifically it might make sense to narrow the spectrum, where will parents go now for affordable help with their children if they have borderline special needs?

Sue Loring, director of the Autism Resource Center of Central MA expressed to me in great detail her thoughts on how the proposed changes could be both positive and negative. Please be aware that the following are her own personal views and do not represent the entire views of the Autism Resource Center nor HMEA.

“As an RN I have an appreciation for the clarity the proposed changes will provide for diagnosticians, researchers and families. The rating scale for severity of symptoms will allow researchers to have consistency in studies as opposed to the practice of asking for participants with vague non specific diagnoses and having to pre screen and screen out subjects. For clinicians and educators the scale will give a better picture of how the person with ASD presents and their needs. Improvements in severity will help validate the efficacy of interventions.

That being said, one has to distinguish the difference between the scientific categorizing of disorders and the culture of the disability. Especially for the higher functioning end of the spectrum, which has embraced the diagnosis of Asperger Syndrome as an identity and have created a culture surrounding the diagnosis similar to the culture of the deaf community. Like that group, the ASD world has polarized, pitting high functioning individuals who embrace accept me as I am and celebrate my gifts against parents seeking a cure or remediation of symptoms for their children. Some Higher functioning individuals presume to speak for all individuals on the spectrum which irritates those who are caring for an individuals who are more severely impacted by ASD. Some HFA folks dismiss severe LFA as being not autistic but intellectually disabled. The pitting of one camp against another has been especially difficult to speak united for the population...

What I think we will see is better diagnosis in the future and a tightening up of the current practice of doctors giving an autism diagnosis so a child can get services. What IS imperative is that those who need care support and treatments are not denied that based on the manipulations of managed care industries to exclude based on this change in diagnostic nomenclature.”

For the perspective of a special education chairperson, I contacted Jenna McMenemy of Auburn, MA, public schools. Like Mary Loughlin and Sue Loring, she also agreed that the new changes are a complicated subject with both potential positives and negatives. In terms of autism research, she felt that, “Perhaps it will spur more medical research to find genetic markers so that a diagnosis can be more precise.” On the other hand, she also told me of how one time, “I have had a friend tell me that their doctor gave their child a diagnosis of autism so that the child could get more services from the school system. That is a concern.” But what about those who do need services? She asked herself, “I wonder what will happen to the group of children who will no longer be found eligible. Will they get the intervention they need? Will the new definition provide more uniformity in diagnosis and reduce the likelihood of a physician potentially giving a diagnosis to facilitate a child having access to more services?” At the end of her interview, she admitted, “This is a tricky issue, and I am not entirely sure what the ramifications are.”

There exists much uncertainty on how the new definition will both help and hinder the future of autism research, treatment, and services. At the moment, it seems only time will be able to tell who is correct regarding the changes. Even if the changes make scientific sense, what do we do about those who are excluded? During my interview with Mary Loughlin, she passionately expressed, “The problem really is, we need to find out why so many have autism and why there appears to be an epidemic separate from over-diagnosis. It may be a burden on society, but these people are here

regardless. We need to take care of them, and we need to improve their quality of life.” Perhaps people with learning disabilities, including those on the spectrum, and other disabilities, need to be taken care of as well in a way so that society does not treat them unfairly.