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Redefining Autism

Over the years, as an advocate for autism awareness and services, I have encountered hundreds of people affected by autism. While each person's experience is of course unique, there are two underlying themes ever-present in their stories: difficulty with diagnosis and frustration with the lack of services available.

A January 19, 2012 New York Times article, "New Definition of Autism Will Exclude Many, Study Suggests," brought into view a plan by the American Psychiatric Association to narrow the definition of autism in the Diagnostic and Statistical Manual of Mental Disorders ("D.S.M"). Apparently a narrowing of what it means to be autistic, or on the autistic spectrum, would be helpful in clarifying ambiguities within the current definition and allow for more precise diagnoses going forward. The effect that a narrowing of that definition would have on access to autism related services, however, is questionable and concerning.

Individuals with autism, and their families, rely on an autism spectrum diagnosis in order to receive the special services that they require. These services include everything from early intervention to family training and support programs. Narrowing the definition of autism could potentially exclude many people from receiving such resources. Even for those that currently receive an autism spectrum diagnosis, quality services are already exceedingly difficult to obtain; budgets have been slashed, service providers are stretched beyond capacity, and the route to actually getting the appropriate services is too often a protracted battle.

As the lead proponent of the City Council's Autism Initiative, I have fought, along with my colleagues, to ensure that funding is earmarked every year in the City budget specifically for autism-related services. The City Council has been able to provide thousands of families with vital support services and resources; unfortunately, the funding is only a drop in the bucket. Too many families in our City still go without the appropriate medical, social and educational resources that are vital to maintaining even the most basic quality of life.

The rise in autism spectrum diagnoses has been drastic and alarming. Most experts and advocates would agree that autism has now reached epidemic proportions. In the aforementioned article, Dr. Fred Volkmar, from the Yale School of Medicine, was quoted as saying “We would nip it in the bud,” referring to the effect that narrowing the definition of autism would have on the epidemic. While I am not a doctor, I simply cannot see how redefining a disorder, and excluding those who would have previously fit under the criteria, stops anything from getting worse. Epidemics should be addressed with research and resources – not redefinition. How would such a change to the D.S.M. affect those who would have otherwise been diagnosed? What about those that we previously diagnosed? Where will people just out of range of this newly defined diagnosis receive the benefits and resources they so desperately need?

Narrowing what it means to be autistic may be beneficial for a more concise medical diagnosis, but the potential human consequences need to be properly considered and addressed. This may be a purely academic issue to a select few, but it is an intensely personal and radically life-changing issue for many more. The American Psychiatric Association must take into account, first and foremost, what impact a redefinition will have on access to the vital services that those affected by autism desperately need and deserve.