Age of First Autism Diagnosis as Seen in the New Jersey Autism Registry

Introduction

The New Jersey Autism Registry (hereafter, the Registry) is a mandatory registry of all children, under the age of 22, living in New Jersey that have a diagnosis of autism. The law that mandated this Registry was passed in 2007, with the rules and regulations that delineate the reporting specifics adopted in 2009. Since then, the Registry has grown considerably from approximately 2000 children registered to over 20,000 registered as of November of 2015. Using the Registry data, this brief examines the age of first autism diagnosis in New Jersey.

According to the Centers for Disease Control and Prevention (CDC), the median age of diagnosis for children with autism spectrum disorder (ASD) is over 4 years of age. This varied by type of ASD, with those individuals having Asperger's Disorder and Pervasive Developmental Disorder-Not Otherwise Specified being older, 6 years and 2 months and 4 years and 2 months respectively (MMWR, 2014). These median ages were considered high since research has shown that children can be reliably diagnosed as early as age 2 (Lord et al. 2006 & Kleinman et al. 2008). Because the age a child is first diagnosed is important for access to autism services, this brief explores the age of first diagnosis in New Jersey using the Autism Registry.

Methods

Data & Variables

The Registry requires all licensed health care providers in New Jersey who diagnose or follow a child with autism in their practice to register that child. The Registry collects a variety of information about a child, including:

- The type of autism, which currently includes all of the Pervasive Developmental Disorders listed in the Diagnostic & Statistical Manual for Mental Disorders (DSM) IV – TR: autistic disorder (299.00), Rett's Disorder (299.80), Childhood Disintegrative Disorder (299.10), Asperger's Disorder (299.80), and Pervasive Developmental Disorder-Not Otherwise Specified (299.80);
- Demographic information;
- The date of first diagnosis, which is the date the child was first diagnosed with autism;
- Instruments/references used to make the diagnosis;
- The health care provider who made the diagnosis or confirmed the diagnosis;
- Age of the child when symptoms were first noted (including parents, pediatricians, or schools); and
- Any comorbid conditions the child has in addition to the autism diagnosis.

Analysis

Age of first diagnosis was calculated using the dates reported by the health care providers minus the child's date of birth. Although the CDC typically reports on the median age of diagnosis, this report will include three types of calculations: the median (the middle value from a list of ages that are placed in increasing order), mean age (the average), and the mode (the most frequent value). The results were then examined by type of autism diagnosis, demographics, and presence of comorbid conditions.

Results

Age of First Diagnosis

Using the data of 14,985 children, the overall mean age of first diagnosis was 5 years old, the median was 3.7 years old, and the mode was 3 years old (See Figure 1). These statistics show a skewed distribution of the ages. Here we see that most children are diagnosed at the age of three (the mode), but that some children are not diagnosed until much later. These later diagnoses ages "pull" the average age out to 5 and therefore the mean is not always the best representation of the whole population. Other statistics such as median and mode should be considered and reported.
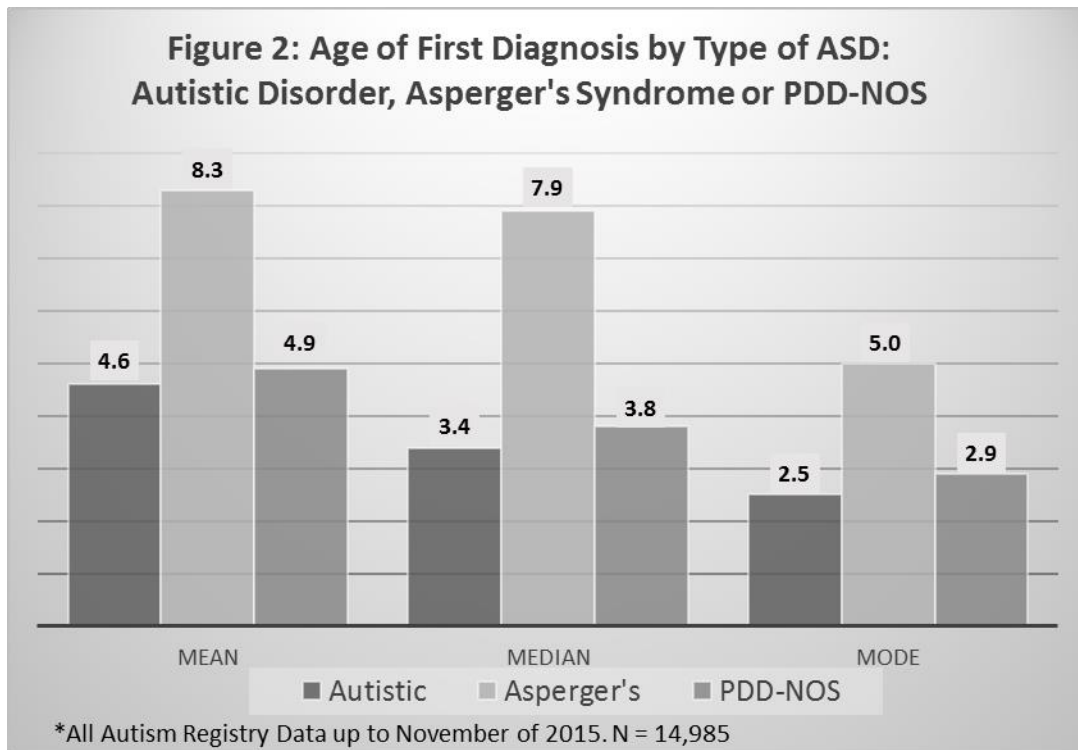
Figure 1: Mode, Median, and Mean Age of First Diagnosis in the New Jersey Autism Registry
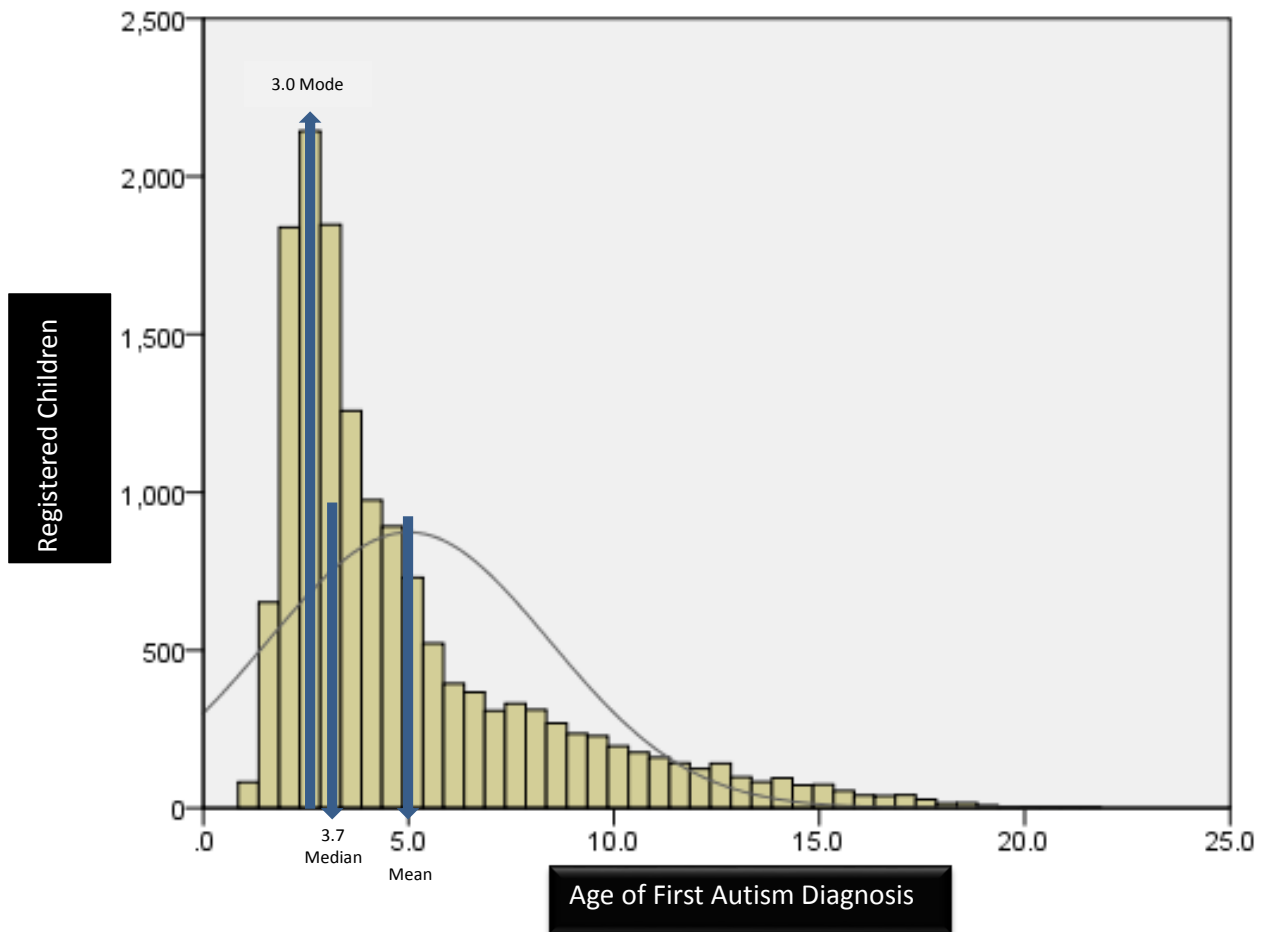
Type of Autism Diagnosis

Significant differences were seen between the three types of autism spectrum disorders (Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified) and

age of first diagnosis (See Figure 2). As expected, Asperger's Syndrome is diagnosed for the first time later for most children, with a mean age of 8.3 years, a median age of 7.9, and a mode of 5.0 years old. This later age of diagnosis could be due to a number of reasons. One reason may be that Asperger's Syndrome mainly presents as deficits in social interaction and repetitive behaviors, but not language delay or cognitive deficits, which are symptoms that are typically picked up by parents, pediatricians, and schools early. Another reason may be that some children are not diagnosed until they present for behavioral or mental health conditions such as mood disorder or conduct disorder. Since behavioral health providers such as psychiatrists also report to the Registry, some of these providers may notice an underlying, secondary condition of Asperger's and therefore the child gets diagnosed at that time.

Figure 2: Age of First Diagnosis by Type of ASD: Autistic Disorder, Asperger's Syndrome or PDD-NOS

*All Autism Registry Data up to November of 2015. N = 14,985

Demographics of the Child

There were no significant differences between males and females in regard to age of first diagnosis. The mean age for both males and females was 5 years old. The median age was 3.7 and 3.6 and the mode was 3.0 and 2.9 respectively. However, age of diagnosis did differ slightly by race/ethnicity (See Figure 3). On average (the mean), White, Not Hispanic, children were diagnosed, later than other children and this can be seen when looking at the mean and median. The mode tells a different story. The most frequent age of diagnosis indicated by diagnosticians for White, Not Hispanic children is 2.5, the youngest age among the race/ethnicity groups. Overall, the age of first diagnosis is not statistically significant among these race/ethnicity groups.

3

Figure 3: Age of First Diagnosis by Race/Ethnicity
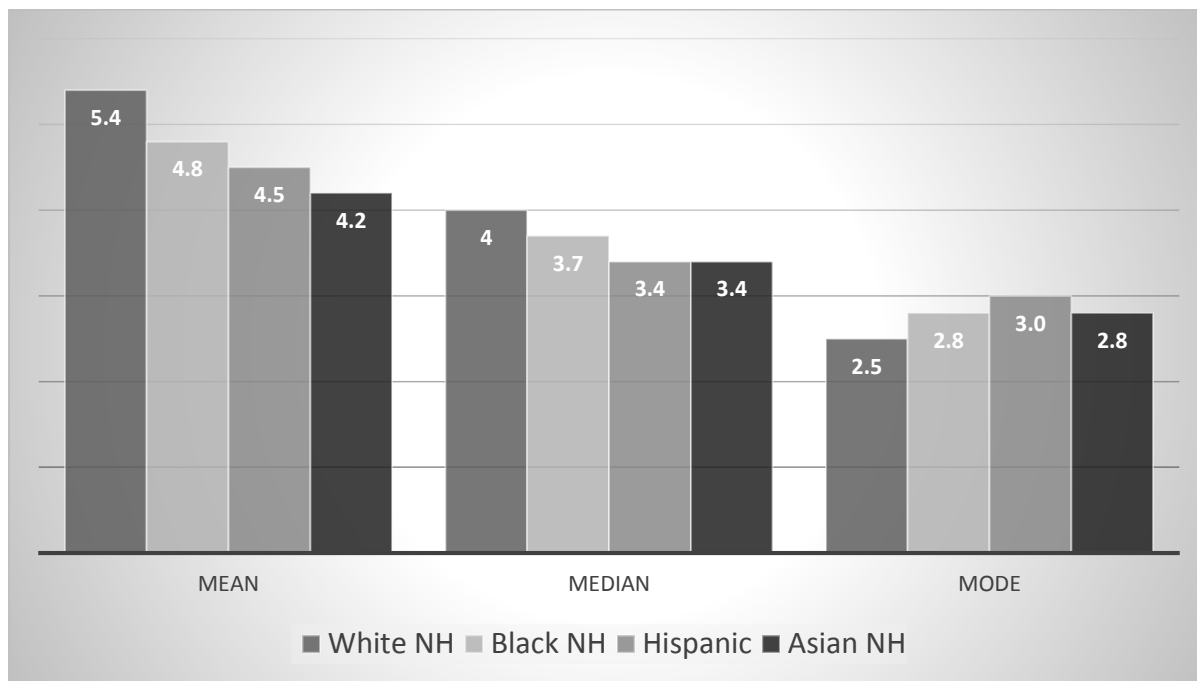
Comorbid Condition

As seen in Figure 4, having a comorbid condition makes a difference at what age the child receives a diagnosis of autism. The type of comorbid conditions included in this analysis were

Figure 4: Age of First Diagnosis by Presence of a Comorbid Condition

*All Autism Registry Data up to November of 2015. N = 14,985
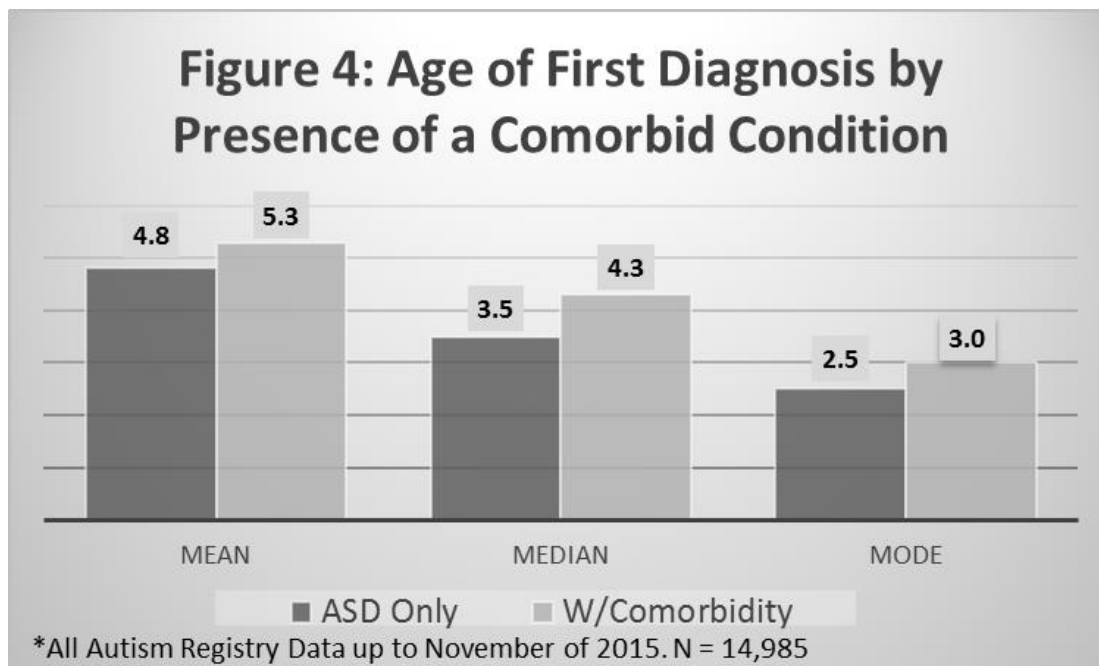
attention deficit hyperactivity disorder (ADHD)/attention deficit disorder (ADD), oppositional defiant disorder, conduct disorder, anxiety, phobias, intellectual disability, mood disorder, depression, and finally seizure disorder/epilepsy. Children with these medical and mental health conditions are diagnosed with autism later than those without these additional conditions. This was true for all comorbid conditions although some of them such as those with an intellectual disability and/or seizure disorder/epilepsy were diagnosed younger than the other mental health conditions.

Receiving a diagnosis later for those with comorbid conditions is not surprising if the child is diagnosed with Asperger's because it typically appears later; however, children with multiple diagnoses should come to the attention of a health care provider sooner rather than later because of the number of behaviors and symptoms that are present. The fact that they are not may indicate a lack of understanding by health care providers between the interaction of autism and other mental health conditions.

Discussion

Our findings indicate that age of first diagnosis can vary by a child's characteristics including the presence of other medical and mental health conditions. The age of first diagnosis in New Jersey's Autism Registry is slightly younger than the CDC's findings on the median age of first diagnosis. Similar to the CDC findings, age of first diagnosis is influenced by the type of autism spectrum disorder, with Asperger's Syndrome being diagnosed later than Autistic Disorder and PDD-NOS. Given that the new Diagnostic and Statistical Manual of Mental Disorders (DSM) version 5 has removed these distinct categories of autism and has created one category of "autism spectrum disorders," there is no way to analytically separate those children with Asperger's Syndrome from the other categories leading to an age of first diagnosis to potentially increase further, especially if we only examine the mean age as opposed to the median and/or mode.

Another important finding was that children with a comorbid medical and/or mental health condition were diagnosed later than those without any comorbid conditions. Given that CDC found that 8.2 out of every 1,000 children have both an autism diagnosis and a psychiatric diagnosis (NJ Autism Study, 2015), further investigation is needed to examine whether certain symptoms and behaviors are masking the underlying autism diagnosis. Autism is typically linked to certain common comorbid conditions and therefore providers need to keep in mind that the presence of one may actually be linked to the presence of another mental health condition. Regardless, programs that address the early identification of children with autism should engage in a thorough assessment of the child's development and go beyond the "milestones" to include whether there is a presence of such behaviors as hyperactivity and/or aggression that may be linked to other disorders. These disorders could mask or impede the treatment of autism and therefore need to be taken into consideration.

References

Kleinman JM, Ventola PE, Pandey J, Verbalis AD, Barton M, Hodgson S, Green J, Dumont-Mathieu T, Robins DL, Fein D. (2008). Diagnostic stability in very young children with autism spectrum disorders. *Journal of Autism Dev Disorder*, *38*(4):606-15.

Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, Pickles A. (2006). Autism from 2 to 9 years of age. *Arch Gen Psychiatry*,63(6):694-701.

MMWR. (2014). *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010*. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm.

NJ Autism Study. (2015). Unpublished data tables obtained by Zahorodny, W. Information on the NJ Autism Study can be found at: http://njms.rutgers.edu/departments/pediatrics/njas/index.cfm.