

ASD Module Script

Module 3: Prevalence

Prevalence Rate: Is there an increase in ASD? Welcome to the module on prevalence rates of ASD. The current increase in ASD diagnoses has been referred to by some as representing an epidemic. The question of whether or not there is an increase in the prevalence of Autism Spectrum Disorders is crucial as it will ideally guide decision making concerning a variety of areas, including funding, programming, legislation, and research. In addition, due to the fact that an ASD diagnosis is enduring and impacts an individual throughout their lifespan, the answer to the question of increasing prevalence rates impacts a wide range of systems.

Prevalence Rate: Prevalence vs. Incidence: It is important to note the differences between prevalence and incidence, which are at times easy to confuse. Prevalence means the proportion of individuals in a population who suffer from a defined disorder. Incidence is the number of new cases occurring in a population over a period of time. For example when someone says “the incidence of ASD has been on the rise in the last ten years,” they are speaking about the number of individuals being born with an ASD. In contrast, if they say, “the prevalence of ASD is rising,” they are referring to the overall proportion of cases in the population.

Prevalence Rate: Autistic Disorder: The rate of 1 in 88 children on average in the United States having an Autism Spectrum Disorder is the prevalence rate that has become widely recognized. This rate comes from the most recent multisite study by the Centers for Disease Control and Prevention and the Autism and Developmental Disabilities Monitoring Network. This rate represents a 78% increase since the first published study by this group in 2002. The largest increases in prevalence over time have been with Hispanic and African American populations.

Prevalence Rate: Across the Spectrum: Other rates have been proposed in the research literature on ASD. For instance, Fombonne published research in 2009 in which he reviewed 43 studies published between 1966 and 2008. Using these studies to compile specific rates of prevalence in the various diagnostic categories, the overall prevalence rate from Fombonne’s study translated into 1 in 150.

Prevalence Rate: So given this information, we are still left to determine...Is there an increase? The answer is unfortunately unclear and given all the evidence can most easily be summed up as...possibly. What is likely happening is that there is not an increase in

children being “born” with an ASD or what we would term new cases; however, there is an increase in existing cases of ASD.

Prevalence Rate: Reasons for Increase: In a review of the literature, there are a number of reasons that have been identified as contributors to the existing prevalence rate of Autism Spectrum Disorders. Some of the reasons we will discuss during our talk include, changes in the diagnostic criteria and assessment practices, inaccurate diagnosis, research methodology, changes in special education policy, increasing availability of services, heightened public awareness, and cultural factors.

Prevalence Rate: Changes in Diagnostic Criteria/Assessment: One of the strongest influencing factors on the prevalence rate is the change in diagnostic criteria and assessment practices. Autism Spectrum Disorders were not included in the DSM until 1980, thus diagnoses given prior to this did not utilize a standard diagnostic criteria. Since this time, the criteria has been expanded and modified, and categories falling under the criteria of ASD have changed. As diagnostic criteria have changed, so have the measures and diagnostic instruments used to identify ASDs. Finally, the International Classification of Diseases or ICD is another means of diagnosing diseases and disorders. It is noted that for a brief period of time in the 1980’s that the diagnostic criteria in the DSM and the ICD were not aligned, which may have resulted in disparities in diagnosis.

Prevalence Rate: Inaccurate Diagnosis: Another factor affecting prevalence is the occurrence of inaccurate diagnoses. In terms of diagnostic instruments, there is variation. For instance, clinically derived diagnoses do not use assessment instruments and may result in inaccurate findings. Next, the amount of experience and training between clinicians that are able to diagnose may be extremely variable. Another issue is that ASDs often share common traits with other communication disorders or social disorders, making differential diagnosis challenging, especially in the light of these other factors. Finally, due to a variety of factors, individuals that may have previously been diagnosed with an intellectual disability in the past are now being diagnosed with Autism Spectrum Disorders.

Prevalence Rate: Research Methodology: When considering research methodology, there are several inherent problems that may be impacting prevalence. Rates are derived in many different ways, which often leads to different rates. One example of this is the difference between the CDC rate and the rate found by Fombonne. Also, there has been increased access to data sources, for instance the CDC used diagnostic data from both medical and school records. Also, if the data used for the prevalence is gathered on children under the age of three, the data and ultimate prevalence rate may be impacted by Autistic regression. Finally, data in many studies is being pulled from a specific age range and then generalized.

Prevalence Rate: Change in Special Education Policies: In 1990, Autism was added to federal special education legislation as one of 14 potential primary educational disability categories. The first year all states had transitioned to using this category was 1994. Shattuck completed a study in 2006 that used longitudinal data from the US Department of Education from 1984 to 2003 to look at increasing prevalence of ASD in special education

identification. According to the study, as a result of the addition of ASD as a disability category, post 1994 rates of Autism in special education experienced an increase from 0.6 to 3.1 per 1,000. At the same time, rates of intellectual disability and learning disabilities, post 1994 decreased to 2.8 and 8.3 per 1,000. It was noted that diagnostic substitution accounted for this change in 50% of the states.

Prevalence Rate: Increasing Availability of Services: Another factor contributing to increasing prevalence is the availability of services. Where we are located in Allegheny County in Pennsylvania, there are at least twenty behavioral health rehabilitation service agencies that are dedicated to providing services to children with ASDs. Often times, the diagnosis of an ASD is the key for families to obtain much needed services, thus diagnostic prevalence rates will likely be impacted. Also, early intervention services have impacted the likelihood of early detection and diagnosis.

Prevalence Rate: Heightened Public Awareness: In recent years, ASD has become more and more present in popular culture and media. One of the most common celebrity examples that comes to mind is Jenny McCarthy, who has been very outspoken concerning her son's experience with Autism. Nationally syndicated television recently produced the T.V. show "Parenthood", which has a child diagnosed with Asperger's disorder as one of the key characters. The show has developed many plot lines around this character, which exemplify the challenges that families and individuals are faced with. We will be discussing the issue of vaccinations at a later point in our talk; however, it may be said that the controversy around vaccines has brought the issue of Autism to the forefront of public awareness.

Prevalence Rate: Cultural Factors: Finally, as Autism crosses all borders and knows no boundaries, cultural factors are another area that is associated with increased prevalence rates. Rates of Autism have been noted to be on the rise in most developed nations; however, there are varying rates across ethnic regions. Issues of acculturation and social factors undeniably impact the differences between nations. For instance, one study found that prevalence rates for Ethiopian children living in Israel were higher than the prevalence rates for Ethiopian children in their native land. It is clear that awareness, capability to treat, and cultural acceptance of a diagnosis are all factors in the prevalence rates internationally.

Summary: Prevalence: You have now completed Module 3: Prevalence. In this module we reviewed reasons for the possible increase of ASDs, including diagnostic criteria and assessment practices, inaccurate diagnosis, research methodology, changes in special education policy, increasing availability of services, heightened public awareness, and cultural factors. Please proceed to the post assessment.
