

The Role of Demographics in the Age of Autism Diagnosis



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Definition

The role of social and demographic factors on the age at which children are diagnosed with ASD.

Historical Background

A growing body of literature has shed light on the nature of the rapidly rising prevalence of ASD. Several variables have been suggested in attempts to explain this trend, with the primary question focusing on whether there is an actual rise in incidence or if an increase in awareness has led to higher rates of diagnosis. Variables such as parental age and environmental pollutants have been suggested as influencers of diagnostic trends (Durkin et al. 2008; Raz et al. 2015a). From the social perspective, contributing factors appear to include increased awareness of ASD, changes in the tools used in screening and diagnosis, lower levels of stigma in societies, and shifts in the diagnostic criteria (Leonard et al. 2010). Taken together, the general consensus appears to be that, while the former factors may play a modest

role, the rise in incidence is not a true increase in the rates of ASD but rather a social shift expressed in higher numbers of individuals being accurately identified and diagnosed (Isaksen et al. 2013).

Given the above, it follows that these social factors affecting the rates of diagnosis of ASD play out in variable fashion across social and demographic contexts. In the ongoing work by the Centers for Disease Control and Prevention's (CDC) Early Autism and Developmental Disabilities Monitoring (ADDM) Network, national prevalence estimates are based on the average across the states monitored. Within that data exists tremendous variability, strengthening the claim that social factors are central in determining rates of diagnosis (Christensen et al. 2019). In a recent publication evaluating data from 2014, the state with the lowest prevalence was Missouri, at approximately 1 in 104 children. The highest prevalence was found in New Jersey, at 1 in 35. Given the lack of any environmental or biological explanations for this stark discrepancy, it is most logically by the fact that New Jersey has more capacity in the form of trained experts with the ability to diagnose young children as well as an early childhood education system capable of screening for and identify the children.

Notably, even with increased awareness, more accurate diagnostic measures, and reduced stigma, families and children that are not seen by trained professionals with specific expertise in the diagnosis of ASD will not be identified.

Current Knowledge

Concurrent to the aforementioned increase in rates of diagnosis of ASD, the professional community's ability to identify and diagnose ASD in early childhood has improved dramatically. Much research now shows that an evidence-based diagnosis of ASD can be provided to most young children with a high degree of confidence between the ages 18 and 24 months and that such diagnoses are typically stable, meaning they remain accurate when the same child is reevaluated at older ages (Guthrie et al. 2013; Ozonoff et al. 2015). Despite these significant advances in our understanding of the early presentation of ASD and our ability to make accurate early diagnoses, the median age at which a child in the United States receives a diagnosis of ASD is 52 months (Baio et al. 2018).

A number of factors appear to contribute to this significant and costly delay in the age at which children are diagnosed. Children with less pronounced autism symptomatology are often diagnosed later compared to children with higher levels of symptom severity, as are children with average verbal abilities, in contrast to those who are minimally verbal (Salomone et al. 2016). The same is true for children from families with low socioeconomic status (SES) and those whose parents do not express concern regarding the presentation of primary symptoms. On a systemic level, children who do not have access to education and health services are often diagnosed later than peers who have such access (Daniels and Mandell 2014; Mazurek et al. 2014; Shattuck et al. 2009).

Children with comorbid health problems or behavioral difficulties are also likely to receive a diagnosis later, since parents or professionals could potentially attribute symptoms of ASD to these co-occurring conditions (Mandell et al. 2005). Such a situation often leads to an incorrect primary diagnosis of another disorder or a missed diagnosis altogether due to diagnostic overshadowing (Fombonne 2005; Goldstein and Schwabach 2004). For similar reasons, children with autism who have experienced adverse childhood experiences, defined as stressful or traumatic experiences, are likely to receive a diagnosis of ASD later than

peers who do not have these experiences (Berg et al. 2018).

Specifically related to SES, studies have consistently found a link between high SES, represented by income, parents' profession, and/or years of parental education, and increased rates of ASD (Durkin et al. 2017; Ng et al. 2017). The primary explanation proposed is that with higher parental education and financial means comes increased access to services, including ASD diagnostic services (Durkin et al. 2010, 2017; Thomas et al. 2012). Work in the United States has found children with ASD from families that speak English as a second language receiving school-based services later than children who come from English-speaking families. When they do eventually receive the services, they receive fewer hours each week than their peers (Nguyen et al. 2016). In contrast, some studies from outside the United States found no particular association between SES and age of diagnosis, and some even found an inverse relationship between family income or parental education and ASD incidence (Khaiman et al. 2015; Larsson et al. 2005). Interestingly, in countries with universal healthcare, such as Canada, Norway, Sweden, and France, where disparities in access to health services between socioeconomic classes are low, higher ASD prevalence was found in lower SES groups, or no link was found between SES and prevalence of ASD (Burstyn et al. 2010; Delobel-Ayoub et al. 2015; Rai et al. 2012).

An extensive review conducted by Daniels and Mandell (2014) examined the association between SES, ethnic or race affiliation, and age of diagnosis. Of the 11 studies that inspected the relationship between SES and age of diagnosis, 5 found an association between high SES and earlier diagnosis, while the remaining studies found no such association. Twelve studies examined the association between ethnic or racial affiliation and the age of diagnosis and revealed contradictory findings. Five of the 12 found that children belonging to ethnic or racial minorities were likely to receive a later diagnosis compared to children of nonminority children, while 5 other studies did not find a correlation between these

factors. The remaining two studies found mixed results, showing that children of the main ethnic group were likely to receive a later diagnosis compared to children of ethnic or race minorities. The researchers posit that these dyssynchronous findings can be attributed to variables that differ between the reviewed studies, such as study duration, sampling method, and the geographic location of the study. The variable findings in this body of literature demand a more nuanced assessment of each individual study, which must each be interpreted within its particular respective context. For instance, a Norwegian study found that ethnicity did not influence the age of diagnosis (Larsen 2015). However, it is imperative to contextualize this finding within the political reality of Norway, where every child has access to health and developmental care at community healthcare centers, regardless of any ethnic difference.

As indicated above, societal shifts in awareness and understanding of ASD are clinically significant and relevant in societal contexts where children and families are able to access proper care. A consistent source of medical or developmental care is essential in order for children to be diagnosed in timely fashion (Emerson et al. 2016). Families with lower SES are also less likely to have such a consistent source of care, thereby minimizing the chance that developmental delays of any kind will be identified and targeted close within the optimal timeframe.

It is noteworthy that the association between consistent care and age of diagnosis was found to differ based on race (Emerson et al. 2016), with African American children's age of diagnosis not decreasing in correlation with consistent care. This could potentially be explained by way of differences in parent and/or professional behavior. Professionals seeing young children of low SES African Americans may be slower to refer the child for a full diagnostic evaluation. Alternatively, or simultaneously, the parents of these children maybe slower to push for such a referral or to question a "wait-and-see" approach.

Future Directions

Further research and taking a more nuanced and subjective perspective on the process of screening and diagnosis are critical. The conflicting findings that exist in this body of literature point to fact that we do not have a clear understanding of these issues. While some studies find strong associations between variables such as SES and age of diagnosis, others do not. Without considering the context for these studies, we are unable to decipher the meaning of the body of work as a whole.

For instance, while studies have examined differences between ethnic and racial groups within the United States, few have done so internationally. A recent study from Israel (Koller et al. 2019) found that the Arab children diagnosed in Jerusalem prior to the age of 6 were nearly all minimally verbal and displayed severe autism symptomatology. While small, this study highlights the fact that while large-scale, population-based studies are necessary to understand broader trends, more nuanced examinations of specific populations and regions are necessary in order to gain actionable data that can lead to the support of specific sectors.

Significantly, the work done in this area has clear and direct relevance for public policy and community mental health. Efforts to raise awareness of ASD and improve capacity for identification of ASD by community professionals can assist in the early diagnosis of children. The heterogeneity of results seen across studies indicates that region-specific differences in screening, evaluation, and diagnostic practice affect the age of diagnosis. The findings of studies conducted in specific geographical regions or municipalities should be conveyed to policymakers and stakeholders in order to utilize the findings as stepping-stones to improved systems of public awareness, screening, and diagnosis. Continued improvements in these both research and research-driven practice may assist the provision of earlier ASD diagnoses and support, which could lead to improved developmental outcomes.

Cross-References

- ▶ [Epidemiology](#)
- ▶ [Prevalence studies](#)
- ▶ [Public health](#)
- ▶ [SES](#)
- ▶ [Underserved communities](#)

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