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How Social and Environmental Factors Affect the Diagnosis and Treatment of Autism Spectrum Disorders

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Many medical conditions have clear causes that can be managed and prevented. For individuals with Autism Spectrum Disorders, however, clear-cut answers are not available. Because there is no blood test to confirm whether an individual has autism, providers must rely on clinical judgment to assess the symptoms in each patient. But diagnosing clinicians have incomplete information, so biases can affect the likelihood that any given patient is diagnosed and treated. According to the Centers for Disease Control and Prevention, no research to date has identified biological or genetic differences that would affect autism's occurrence across different groups. Yet there are clear gender, racial, and ethnic disparities in the diagnosis and treatment of autism.

Given the uncertainties, the context of patients' lives coupled with implicit or explicit bias on the part of clinicians can dramatically influence a patient's likelihood of being diagnosed. The patient's context can be thought of as patterned in concentric circles around a bullseye. The narrowest circle includes individual factors. Circles then move outward to the patient's family and neighborhood, and then to the public health and other policies in his or her surrounds. Clinicians need to consider all of these factors, and how they relate to each other, when assessing whether an individual has an autism spectrum disorder and then considering the services and treatments to recommend to those so diagnosed.

Individual, Family, Community, and Policy Factors

Each set of factors influencing diagnosis and treatment can be explained in turn.

Individual factors**,** the easiest to identify and routinely measured, include immutable characteristics like race and sex and developmental factors like intellectual disability or epilepsy. Research shows that individual characteristics affect disparities in diagnosis and treatment. For example, males are four times more likely than females to be diagnosed. And more non-Hispanic whites are diagnosed with autism than Hispanics or non-Hispanic blacks. Clinician biases and can come into play. With patients from certain cultures, for example, clinicians may be quicker to assign symptoms of autism to "community deprivation" or behavioral issues. But such presumptions can erode families' trust in the system and suppress their ability or willingness to advocate for their children. In the worst possibility, clinician ignorance of their own biases and can lead to missed diagnoses and failures to connect patients with needed resources.

Family factors include close social relationships, both actual kin ties and links to close friends and other support networks. As factors often linked to social and economic status, social supports and family structures can determine whether a family has the resilience and capacity to meet the needs of a child with special health care needs, including by bearing the direct and indirect costs of treatment.

Community and neighborhood factors include organizations, institutions, and other formal and informal networks in a patient's or family's immediate sphere of influence. Public health researchers often note that health can be more accurately described by one's zip code than by one's genetic code, because people with similar characteristics tend to cluster in neighborhoods. Cultural or ethnic enclaves may include high numbers of immigrants. Rural, urban, and suburban contexts are strong markers of availability of services. Due to housing, taxation, and other local policies, individuals with similar incomes and racial and ethnic backgrounds are likely to live in the same geographic areas – and low-income and minority areas often have environmental risk factors like chemical exposure and lack of access to care. Certainly, medical specialists are less likely to locate their practices in lower-income areas.

Research has found links between autism as reported by parents and neighborhood risks as well as weak social capital ties. Studies have also shown that children diagnosed with autism are more likely to have experienced adverse childhood events such as witnessing or being a victim of violence. Awareness of these community factors can help clinicians better understand environmental risks in neighborhoods, as well as the access of their residents to services.

Policy factors include laws and social norms at the local, state, regional, national, and global levels. In the United States, the Individuals with Disabilities Education Act mandates the delivery of free appropriate public education to people with disabilities, including those with autism. The Americans with Disabilities Act prohibits discrimination against people with disabilities in all areas of public life. These two national policies reduce stigma and incorporate individuals with disabilities like autism into society. These laws ensure that families have protections for their children if they are diagnosed with autism. State-level insurance mandates and Medicaid coverage for services can also affect access to care, by encouraging the growth of provider networks and giving families some financial relief in paying for insurance.

Why Knowledge of Risk Factors Matters

Research suggests that ethnic minority children and white children have similar levels of access to "medically necessary" treatments. But significant gaps open when members of these groups seek supplemental treatments, including some therapies known to be most effective in managing autism. Clinicians can improve their efforts if they become aware of these disparities – and the social rather than biological reasons why they occur. It is not enough simply to avoid personal bias, because frequently used diagnostic tools may not be sufficiently attuned to cultural or gender differences among patients who seek help.

In recent years, many have called for more finely-tuned, cross-culturally reliable diagnostic tools for diagnosing autism. Research shows that disparities in diagnosis are significant. But because little evidence exists on inherent biological or genetic variation in risk for autism across racial, ethnic, and socioeconomic groups, clinicians must carefully weigh the individual, family, community, and policy factors that can affect diagnosis and treatment. Until certain tests arrive, clinician awareness and good judgement must be grounded in understanding of the full range of influences that can be relevant to the identification and treatment of autism disorders.

Read more in Anne E. Brisendine "Autism Spectrum Disorders and Social Ecological Models: Understanding How Context Drives Prevalence" (Working Paper, 2017).