

Perspectives on Genetic Counseling for Autism Spectrum Disorder at Boston Medical Center

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Autism spectrum disorder (ASD) is a neurodevelopmental diagnosis characterized by deficits in communication and social interaction, as well as limited or repetitive actions or interests. ASD is a 'multifactorial' condition influenced by both genetic and environmental components; it is recommended every patient with ASD be offered a genetics evaluation. Previous studies report parental misconceptions, a desire to learn more about genetics, and an increased need for educational support and counseling. Understanding parents' perceptions of and experiences with genetic testing for ASD can be useful for the development of tailored genetic counseling and strategic care planning. In this study, a mixed-methods survey inquired about genetic testing uptake, impact of results, and understandability of information. Participants were recruited through the Boston Medical Center Autism Program. Survey results informed reasoning for pursuing genetic testing, priorities for communication, comprehension and utility of genetic information, and challenges with the genetic testing process. These results emphasized the benefits of post-test counseling, psychosocial support, facilitation of blood sample alternatives, and education about ASD etiology.