The ASD Demonstration Project: A Multi-center study to expand our understanding of ASD

childhood disability LINK

Summary

Autism spectrum disorders (ASD) encompass a range of developmental disorders that are now diagnosed in 1 of every 100 Canadian children. ASD's increasing frequency highlights a need to develop better strategies for early detection and treatment. NeuroDevNet is now initiating an expansive study that aims to do just that. Its ASD Demonstration Project will research the mechanisms behind ASD with the hopes of enhancing current strategies for diagnosis, prevention, and treatment. This expansive, multicenter study has several components and several goals. High throughput DNA sequencing will allow researchers to characterize the genomes of individuals with ASD and their family members, as well as unaffected individuals, to identify rare genetic variations that characterize the disorders. Brain development in affected individuals will then be monitored using conventional magnetic resonance imaging (MRI) and diffusion tensor MRI (DTI), and social competence and emotional-behavioral adjustment will also be monitored in a longitudinal study. Ultimately, phenotypic characteristics in behavior and brain development will be linked back to particular genetic variations. Finally, workshops will be held with important stakeholders to understand how to best translate research findings to clinical use.

What families should know

ASD has a significant effect on the lives of affected children as well as their families. Children with ASD experience difficulties in socialization, communication, and adaptation to new situations, and they often require special educational assistance. Families may feel economic as well as emotional challenges, as they try to pay for educational needs, social services, and account for lost income. ASD is associated with a higher level of family stress than many other developmental disorders. NeuroDevNet hopes that the ASD Demonstration Project will improve clinical care and the daily lives of individuals with ASD and their families by promoting earlier diagnoses, concrete prognoses, and individually targeted treatments.

What practitioners should know

Several studies of children affected by ASD and their twins and other family members show strong evidence for a genetic component to the disorders. Nonetheless, specific gene variants have not yet been implicated in ASD. Therefore this study aims to characterize the genomes of large numbers of children affected by ASD and their families, and then to follow these children, monitoring brain development as well as social and behavioral development. NeuroDevNet hopes that this long term analysis will provide insight into which rare genetic variants may be significant diagnostic and prognostic markers of ASD. Earlier diagnosis and an understanding of ASD variations will allow for earlier and more targeted interventions, which have been shown to promote a better patient outcome.

Reference

Zwaigenbaum, L., Scherer, S., Szatmari, P., Fombonne, E., Bryson, S., Hyde, K., et al. (2011). The NeuroDevNet Autism Spectrum Disorders Demonstration Project. Seminars in Pediatric Neurology, 18, 40-48.

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