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Autism Spectrum Disorders: Improving the Lives of Children and Their Families

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MATERIALS

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This brief summarizes a longer Social Policy Report

Autism Spectrum Disorders Diagnosis, Prevalence, and Services for Children and Families

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Why Does This Matter?

About 1 in 110 children in the United States has an autism spectrum disorder (ASD), a diagnosis considered rare two decades ago but growing today. Amid rising health care expenditures, ASD costs American families an estimated $3 to $5 million over a lifetime, and it's estimated to cost society almost $90 billion yearly. Compared to others with specialized health care needs, children with ASD receive fewer services. And because so few services are reimbursed by health insurance, families of children with ASD have more financial problems.

Intervening early in the lives of children with ASD is likely to provide substantial savings to society. Relatively minor changes in independence and adaptive skills can save significant amounts of money.

Policy Implications

To help improve the lives and independence of children and adults with ASD, policymakers should:

- Ensure that health insurance and public funding policies support evidence-based programs, provide families access to appropriate diagnostic evaluations that go beyond a brief doctor's visit to allow for comprehensive planning, and cover such mental health services as cognitive and language testing.
- Support the development of a standard assessment protocol that includes consideration of both socialcommunicative issues and language and cognitive development. Such a protocol will enable practitioners to better tailor interventions since children's profiles can differ markedly across these two areas. As ASD has become a more heterogeneous category, one-size-fits-all approaches to diagnosis and assessment are not appropriate; a standard protocol would help ensure appropriate treatment.
- Support federal standards and state programs that identify and serve children with ASD, given that different states count children with ASD in different ways, and funding decisions are made based on those counts.
- Ensure that effective approaches to both diagnosis and treatment are implemented among racial and ethnic minority and low-income children.

What the Research Says

- Children with ASD vary greatly in terms of their needs, levels of language development, IQs, and behavior.
- There are disparities across races and ethnic groups in diagnoses of ASD. Later and fewer diagnoses in children of racial/ethnic minorities and children with less-educated parents are likely to have significant effects on access to services and development.
- Evaluations involving team members from different disciplines provide the best opportunity to assess children's difficulties and symptoms, gauge the severity of symptoms, and create appropriate treatment plans.
- Procedures vary widely among practitioners: Half to three-quarters of doctors don't regularly use formal developmental screening tools recommended by the National Research Council and the American Academy of Pediatrics.
- Specific approaches that have been tested and found effective fall into two broad categories: focused interventions (practices intended to change a targeted behavior) and comprehensive treatments (intense practices designed to have a broad impact on core features of ASD). Both require months of daily treatment. The number of rigorously evaluated treatment approaches remains small.

Facts at a Glance

- In the past 30 years, public awareness of autism has risen significantly; today, ASD is recognized as a set of common developmental disorders. At the same time, there have been considerable increases in the number of children estimated to have ASD.
- ASD begins before age 3 and is marked by deficits or unusual behaviors in 1) how individuals interact with others, 2) communication, and 3) repetitive interests and behaviors.
- Autism spectrum disorders include autistic disorder, Asperger's syndrome, and pervasive developmental disorders not otherwise specified.
- Autism occurs about four times more often in boys than girls and is sometimes accompanied by intellectual disability.
- Because so few diagnostic or treatment services are reimbursed by health insurance, the responsibility often falls on families and schools to decide about the intensity and types of treatments and educational services, and to provide funding.
- The diverse nature of ASD and the need for treatments to be family-centered offer challenges to identifying which treatments are most appropriate for children and families.

This brief summarizes a longer *Social Policy Report*, "Autism Spectrum Disorders Diagnosis, Prevalence, and Services for Children and Families," by **Catherine Lord**, Director of the University of Michigan Autism and Communication Disorders Center, and a Professor of Psychology, Psychiatry, and Pediatrics, and **Somer L. Bishop**, Assistant Professor in the Division of Developmental and Behavioral Pediatrics at the Cincinnati Children's Hospital Medical Center.