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Primary Medical Care For Children With Autism Needs Improvement

ScienceDaily (Apr. 6, 2007) — Children with autism do not receive the same quality of primary care as children with other special health care needs, according to research from the University of Minnesota Medical School.

A study published in the Archives of Pediatrics and Adolescent Medicine found that parents of children with autism were less likely to report that their children received the type of primary care advocated by the American Academy of Pediatrics (AAP) when compared to parents of children with other special health care needs. The "medical home model," which is defined by the AAP as accessible, continuous, comprehensive, family-centered, compassionate, culturally effective, and coordinated with specialized services was used as a measure for ideal primary care of children.

"This study shows that children with autism are less likely to receive the type of primary medical care that we hope for all children," says principal investigator Allison Brachlow, M.D., research fellow at the Department of Pediatrics. "With increasing numbers of children diagnosed with autism, it is imperative to understand how to provide optimal care for these children."

Specifically, Brachlow found that parents of children with autism were less likely to report their child's care was family-centered, comprehensive, or coordinated. For example, parents of children with autism were less likely to report that their child's primary care provider spent adequate time with them, offered understandable explanations, or discussed outside services, such as speech and occupational therapies. Furthermore, parents of children with autism were more likely to report difficulties obtaining subspecialty care, such as referrals to a gastroenterologist or other subspecialty doctor.

Researchers analyzed data from the National Survey for Children's Health (NSCH) which surveyed 102,353 parents or legal guardians of children under 18 across the nation. Of this number, 495 children were identified as having autism and 18,119 were defined as children with other special health care needs such as asthma, attention deficit disorder, behavioral conduct problems, and depression.

As a disease, autism presents challenges which may contribute to difficulties in providing primary care.

"While there is a recognized genetic component to autism, the cause is still unknown. Additionally, the diagnosis of autism is clinical, meaning there are no blood tests to determine if a patient has autism. Currently, there are many therapies and treatments for autism, each with varying degrees of supporting scientific evidence." Brachlow notes, "Epidemiological research is challenging because children with autism appear to be a heterogeneous group. Further research is needed to determine and implement the best models of primary care delivery for children with complex medical conditions, such as autism."

According to the Autism Society of America, autism is estimated to affect approximately one in every 150 births. This accounts for approximately 1.5 million Americans who have been diagnosed with some form of autism, which varies in its severity. It is expected that the number could reach 4 million within ten years.

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University of Minnesota (2007, April 6). Primary Medical Care For Children With Autism Needs Improvement. *ScienceDaily*. Retrieved May 10, 2010, from <http://www.sciencedaily.com/releases/2007/04/070402214953.htm>

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