

University of Pennsylvania/The Children's Hospital of Philadelphia Center for Autism and Developmental Disabilities Epidemiology



The Children's Health Act of 2000 directed the Centers for Disease Control and Prevention (CDC) to establish regional centers of excellence for autism spectrum disorders (ASDs) and other developmental disabilities. CDC is now funding **Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)** in California, Colorado, Maryland/Delaware, North Carolina, and Pennsylvania. For information:

<http://www.cdc.gov/ncbddd/dd/ddautism.htm>.

The University of Pennsylvania/The Children's Hospital of Philadelphia Center for Autism and Developmental Disabilities Epidemiology is the CADDRE program studying ASDs in Pennsylvania. The Pennsylvania counties in the project are Chester, Montgomery, and Philadelphia.

The Pennsylvania center will conduct four projects:

Monitoring Activities

It is not currently known how many children living in Pennsylvania have an ASD. During the period 1992 through 2001, the number of children served in Pennsylvania under the Individuals with Disabilities Education Act (IDEA) increased 855%. IDEA is the federal law that supports special education and related services for children and youth with disabilities. In the three counties in this project during the 2000-2001 school year, over 2,350 children ages 3-5 years received special education services - 613 with autism classifications, and 10,449 children aged 6-9 years received special education services - 430 with an autism classification. There are additional children with ASDs who are in other types of special education classes, regular education, private school, or home school. The Pennsylvania center will use multiple sources to obtain a more complete estimate of the number of children in the project area with an ASD. The center will study whether ASDs are more common in some groups of children than in others and whether the number of children with ASDs is changing over time. The monitoring will focus on 3 through 5-year-old children.

CADDRE Case Cohort Study

The Pennsylvania center will work with the other CADDRE programs to find causes of ASDs or factors that make it more likely that a child will have an ASD. Families who take part in the study will answer survey questions; children with ASDs will be tested, and staff will look at children's birth records. Children aged 3 to 5 years will be included in the combined centers study. Children with ASDs will be compared with children who do not have an ASD.

Special Studies

The Pennsylvania center is interested in studying genetic and environmental factors and their roles in causing ASDs. The Pennsylvania Center is also interested in screening children at an early age for signs of an ASD. The first project will focus on screening toddlers aged 18 to 24 months for early signs of ASDs. After a child is diagnosed as having an ASD, the Pennsylvania center will study ways to help parents manage the issues that arise as they seek medical and other treatments as well as educational and other services for their child.

Sharing Information and Community Outreach

The Pennsylvania center plans to train nurses, physicians, educators, and other providers of health and educational services to screen children for signs of a DD and ASDs. Information will be shared through mailings to parents and support groups, and the media, and through scientific publications, and presentations to teachers, clinicians, and other professionals. A research registry, currently under development, will link families to researchers.

For further information, please contact:

Ellen Giarelli, EdD, RN
Research Projects Director
University of Pennsylvania, School of Nursing
420 Guardian Drive
Philadelphia, PA 19104
Phone: (215) 746-0041
E-mail: giarelli@nursing.upenn.edu
CADDRE@nursing.upenn.edu



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