How many children have autism or an autism spectrum disorder? Wisconsin is currently one of 13 states funded by the Centers for Disease Control and Prevention (CDC) working to answer this critical question. As part of the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network, Wisconsin is counting the number of 8-year-old children with autism in the southeastern region of the state. The data collected for this monitoring system have many uses for Wisconsin.

Wisconsin needs accurate information about the number of children with autism and other developmental disabilities.

How Does Autism Surveillance Lead to More Effective Programs and Improved Services Specific to Wisconsin?

- Accurate information on the number of children with autism in the State will lead to better personnel training and more effective use of limited resources.
- Knowledge of the number of children with autism allows state and local departments to obtain necessary financial support to meet the demand for services and treatment.
- Policymakers can use the information to make informed planning decisions about services, resource allocation, professional trainings, and outreach. Wisconsin-specific data will drive a state plan that addresses the needs of the state’s people.
- Trends can be monitored, allowing decision-makers to measure the effectiveness of services and policies.
- Disparities in access to services (by race/ethnicity, economic status, and geographic location) can be identified and corrected.
- WISADDS outreach activities increase public and professional awareness of disabilities, needs for support and services, and best practices for service provision.

Statement of the Problem: Lack of Access to Education Records Limits Autism Surveillance in Wisconsin

Each year since 2003, the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS, [http://www.cdc.gov/ncbddd/autism/states/WI-ADDM.pdf](http://www.cdc.gov/ncbddd/autism/states/WI-ADDM.pdf)) has received funds from CDC to participate in the ADDM Network. While most states in the ADDM Network review both education and medical records to determine the number of children with autism, Wisconsin is one of a few that has been unable to access education records due to concerns that the surveillance system may violate the Family Educational Rights and Privacy Act of 1974 (FERPA), a law that protects the privacy of student education records. Although no personally identifying information is retained in the ADDM Network database, and extensive procedures are followed to protect the confidentiality of information from medical and education records, concerns about FERPA can be a barrier to autism surveillance. One way in which other states in the ADDM Network are granted access to education records by their state departments of education is through an exception recognized under FERPA, that allows organizations to conduct studies for, or on behalf of, schools for the purposes of improving instruction.

Why is this important now? Beginning in 2010, states will no longer be eligible for CDC funding to participate in the ADDM Network unless they have established formal agreements or Memoranda of Understanding allowing schools and public health authorities to share information. Thus, Wisconsin is at risk of losing federal funding for surveillance of autism and WISADDS will discontinue unless such an agreement can be established.

Suggested Action

Your support is needed to urge leadership in Wisconsin to find a way to continue autism surveillance in Wisconsin. We ask that the Community of Practice and other stakeholders endorse continued access to federal funding for autism surveillance in Wisconsin by writing letters of support to the Governor, the Superintendent of the Department of Public Instruction, and the Secretary of the Department of Health Services.

Please contact WISADDS Project Director, Dr. Maureen Durkin, at (608) 263-2128, Project Coordinator, Carrie Arneson, at (608) 263-8222 or clarneso@wisc.edu with questions or concerns.