



## Utah Autism and Developmental Disabilities Monitoring (ADDM) Project

**The Autism and Developmental Disorders Monitoring Network (ADDM Network).** The Centers for Disease Control and Prevention (CDC) is supporting researchers in many states, including Utah, to develop programs to monitor the prevalence of autism spectrum disorders (ASDs). The goal of the *ADDM* Network is to provide comparable, population based estimates of the occurrence of autism and related disorders in different states, over time. For more information:

[www.cdc.gov/ncbddd/dd/ddautism.htm](http://www.cdc.gov/ncbddd/dd/ddautism.htm).

**The Utah Registry of Autism and Developmental Disabilities (URADD)** is a population-based project to determine and monitor the number of children in Utah with ASDs and mental retardation. The primary focus of the project is a CDC-sponsored public health registry of children with ASDs or mental retardation, or both in the year 2002. The investigators are members of the Utah Department of Health's Children with Special Health Care Needs Bureau and the University of Utah School of Medicine's Department of Psychiatry. URADD is a collaborative undertaking of CDC, the Utah Department of Health, and the University of Utah School of Medicine's Department of Psychiatry.

**What part of Utah is included in the URADD?** The CDC-funded public health registry will center on Davis, Salt Lake, and Utah Counties, where about 70% of Utah's inhabitants live. The Utah Department of Health will develop a self-reporting registry to include the entire state. About 33,000 babies are born in the 3 county area each year - about 47,000 in the entire state.

**What is the age of the children in the study?** The public health registry will focus on children who turned 8 in 2002. The self-reporting registry will include all ages.

**How many people 3-21 years of age are classified as having autism by the Utah State Office of Education?** During the 2001-2002 school year, the Utah Office of Education reported serving 830 students classified as having autism.

**How common are autism spectrum disorders (ASD) among children who live in Utah?** We do not know the current number of children with ASDs living in Utah. The UCLA-University of Utah Epidemiologic Survey of Autism Prevalence Study in 1983 estimated the incidence rate of autism in Utah to be 4 in 10,000. The URADD project will help us learn how many children now living in Utah have any of the ASDs.

**What kinds of education and training programs will the project offer to people who work with children who have ASDs?** URADD will offer training for Utah educators and community health providers on ASDs and URADD activities on a yearly basis. Training for community health providers will be coordinated through continuing education programs. URADD's activities and findings will also be presented as part of the Autism Society of Utah's annual conference.

**What are some of the other programs in Utah that work with children with ASDs and their families?** Other ASD programs in Utah include the Autism Society of Utah; the Utah Parent Center; the Carmen. B. Pingree School for Children with Autism; the Utah Department of Health's Children with Special Health Care Needs Bureau; the Utah Division of Services for People with Disabilities; the University of Utah's Child, Adolescent and Young Adult Specialty Clinic; and the University of Utah's Neurobehavior Clinic.

**Do any laws or statutes in New Jersey have to do with ASD?** Not at present

**Does the study's staff work with any other monitoring programs in the state?** URADD will coordinate with Utah's Birth Defects Network; Vital Records; Hearing, Speech and Vision Services; the Computerized Health Advanced Record Management system; and the Baby Watch Early Intervention Program.

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