



State of Utah

GARY R HERBERT
Governor

SPENCER J. COX
Lieutenant Governor

**Utah Department of Health
Executive Director's Office**

Joseph K. Miner, M.D., M.S.P.H., F.A.C.P.M.
Executive Director

Division of Family Health and Preparedness

Paul R. Patrick
Division Director

**Children with Special Health Care Needs
Bureau**

Noël Taxin, M.S.
Bureau Director

12/20/2019

Dear Parent/Guardian:

This letter is to inform you about your rights pertaining to the Utah Registry of Autism and Developmental Disabilities (URADD) and the Centers of Disease Control and Prevention's Utah Autism and Developmental Disabilities Monitoring Network (UT-ADDM). URADD is a partnership between the Utah Department of Health's Bureau of Children with Special Healthcare Needs and the University of Utah Department of Psychiatry and has been measuring the prevalence rates of Autism and other Special Needs classifications in Utah since 2002. School and health information are essential to ensure accurate and reliable Autism prevalence estimates. These estimates are used by the State of Utah, the Utah State Board of Education (USBE) and your Local Education Agency (LEA) to improve the quality of instruction for students receiving special education services. This includes access to diagnostic services, early intervention, special education, and support for parents and individuals with Autism and other Special Needs as they age into adulthood.

Parental/Guardian Rights:

URADD receives information on all children who are eligible for special education services through the USBE. If your child was on an IEP from January 1st, 2016 to December 31st, 2016 or January 1st, 2018 to December 31st, 2018, the USBE intends to share your student's data with the URADD and UT-ADDM. As a parent of a child who is eligible to receive special education services, you have a right to opt your child out of the URADD and UT-ADDM education databases at any time.

What should I do if I do not want the USBE to share my student's information with URADD/ADDM? In accordance with the Utah Student Privacy Act (53E-9-308), parents/guardians have the right to exempt the sharing of their child's data with URADD/ADDM. If you would like to request that your student's data is not shared, please notify your district or charter school special education director, director, Mary Johnston at 801-476-4627 or mjohnston@hmcharterschool.org within 30 days of receiving this notice. This is called "Opting Out." Opting Out means your student's information will not be shared with URADD/ADDM. If you want the USBE to share this information with URADD/ADDM, you don't need to do anything. If you decide to Opt-Out, your student's special education services will not be affected in any way.

If, at a later date, you would like to have your student's data deleted from URADD/ADDM educational database, you can. As a parent/guardian, you are entitled to contest and seek to amend, expunge, or destroy any data shared with ADDM/URADD by the USBE for any reason. For more information, please contact Colin Kingsbury by phone at 801-584-8455 or via email at ckingsbury@utah.gov.





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Data Security

Your student's Personally Identifiable Information is **NOT, and never will be shared**, with non-URADD employees or the CDC. Once all data are collected, all Personally Identifiable Information is removed from the dataset prior to analysis, and report of findings only include aggregate information. For example, 1 in 54 8-year-olds in Utah have Autism.

All Student Data are stored securely on a Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) compliant system. The URADD and UT-ADDM databases are located on password-protected and data encrypted servers behind University of Utah firewalls and are accessible only to URADD employees. All desktop and laptop computers are full-disk encrypted. Access to URADD and UT-ADDM data is audited quarterly by the Utah Department of Health's URADD Data Steward. All active URADD and UT-ADDM employees with access to data can be found at (cshcn.link/ADDM). If you have any questions regarding data security, please contact Colin Kingsbury, URADD Data Steward at the Utah Department of Health at (801) 584-8455 or by email at ckingsbury@utah.gov.

Colin Kingsbury, MSc
URADD Oversight Committee Chair
URADD Data Steward
Autism System Coordinator, CSHCN, UDOH

Attachments:

- Community Resources based on Special Education Services
- Website information for UT-ADDM and URADD



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Community Resources

Below are links to community resources for families of children with special healthcare needs. These links are organized under special education classifications and have been created by The Utah Department of Health's Bureau of Children with Special Healthcare Needs. This outreach effort is also supported by our participation in the ADDM Network.

Resources:

Autism

Evaluation Services:
cshcn.link/findeval

Applied Behavioral Analysis Providers:
cshcn.link/aba

Post-Secondary Education: cshcn.link/school

Housing and Independent Living:
cshcn.link/living

Employment: cshcn.link/jobs

Ten Tips: cshcn.link/tips

Transition Tool Kit: cshcn.link/toolkit

What Can You Do Before 18: cshcn.link/acu18

Speech/Language Impairment

Speech and Language Providers:
cshcn.link/speech

Intellectual Disability

Integrated Services Program: cshcn.link/isp

Deaf/Blindness

Utah School for the Deaf and Blind:
<https://www.usdb.org/>

Developmental Delay

Integrated Services Program: cshcn.link/isp

Emotional Disturbance

Integrated Services Program: cshcn.link/isp

Hearing Impairment/Deafness

Early Hearing Detection and Intervention:
cshcn.link/edhi

Multiple Disabilities

Integrated Services Program: cshcn.link/isp

Orthopedic Impairment

Integrated Services Program: cshcn.link/isp

Other Health Impairment

Integrated Services Program: cshcn.link/isp

For more information about the ADDM Network:

<https://www.cdc.gov/ncbddd/autism/addm-community-report/what-is-addm-network.html>

For more information about URADD:

www.utahautismregistry.org