



UTAH DEPARTMENT OF HEALTH

Children With Special Health Care Needs

Autism in Utah: A Closer Look

Colin Kingsbury

Autism System Development



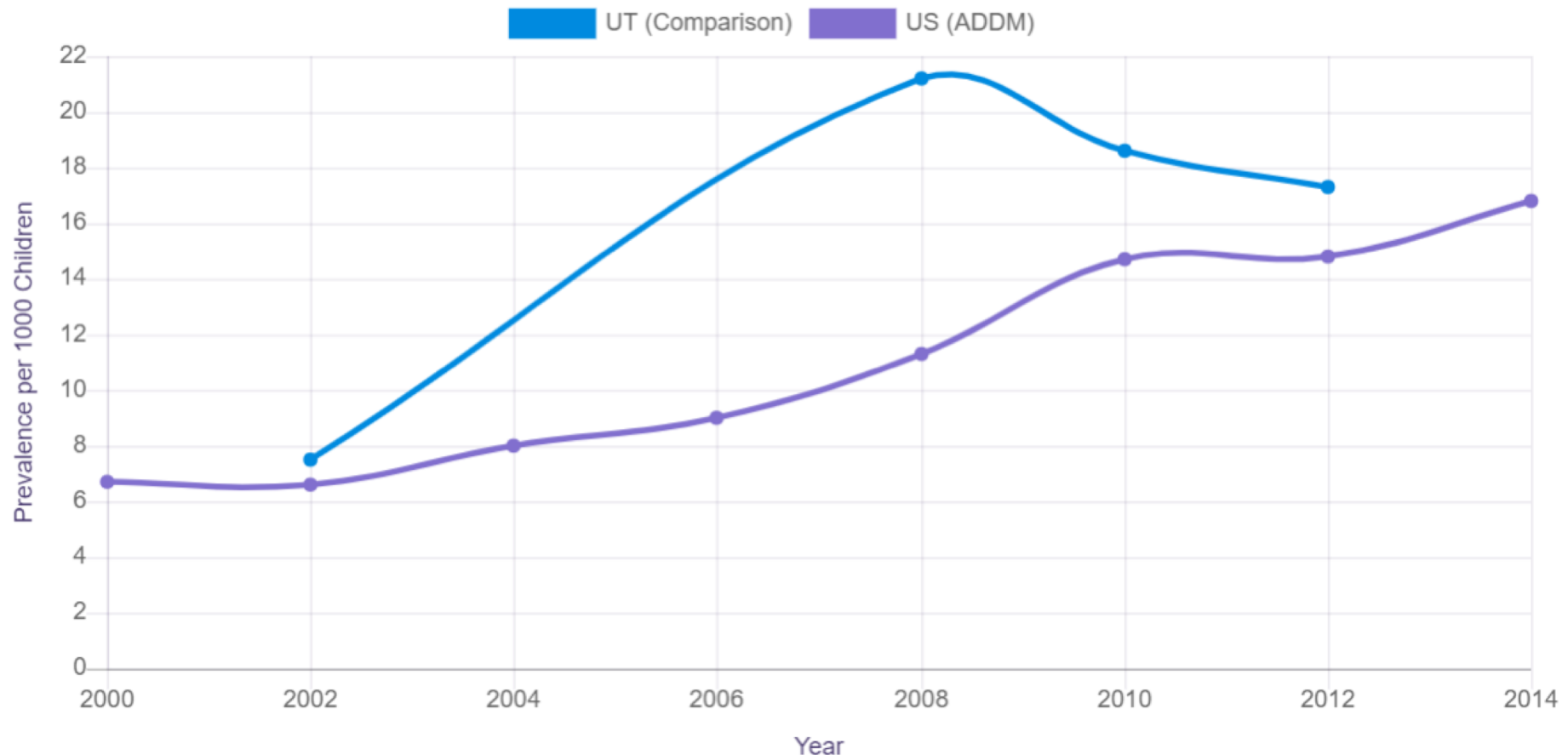
Mission:

The Autism Systems Development Program seeks to advance, educate and empower the lives of individuals affected by Autism Spectrum Disorder (ASD) in Utah by monitoring occurrence, reducing the age at first diagnosis, referring to services, facilitating research, and providing education and outreach.

Autism System Development



ADDM Network estimates for overall ASD prevalence in US over time
compared to prevalence estimates in UT

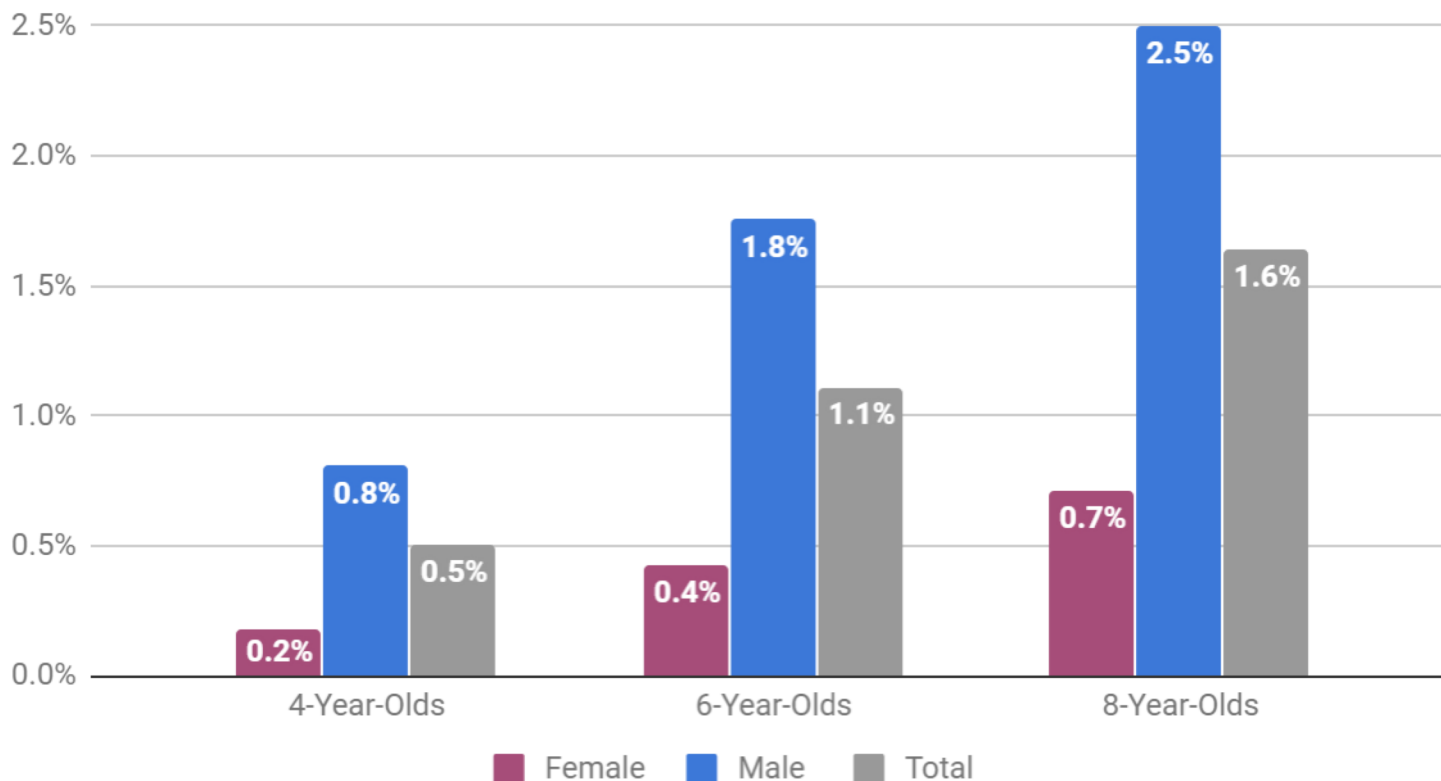


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Monitoring Occurrence:

Male to Female Ratio

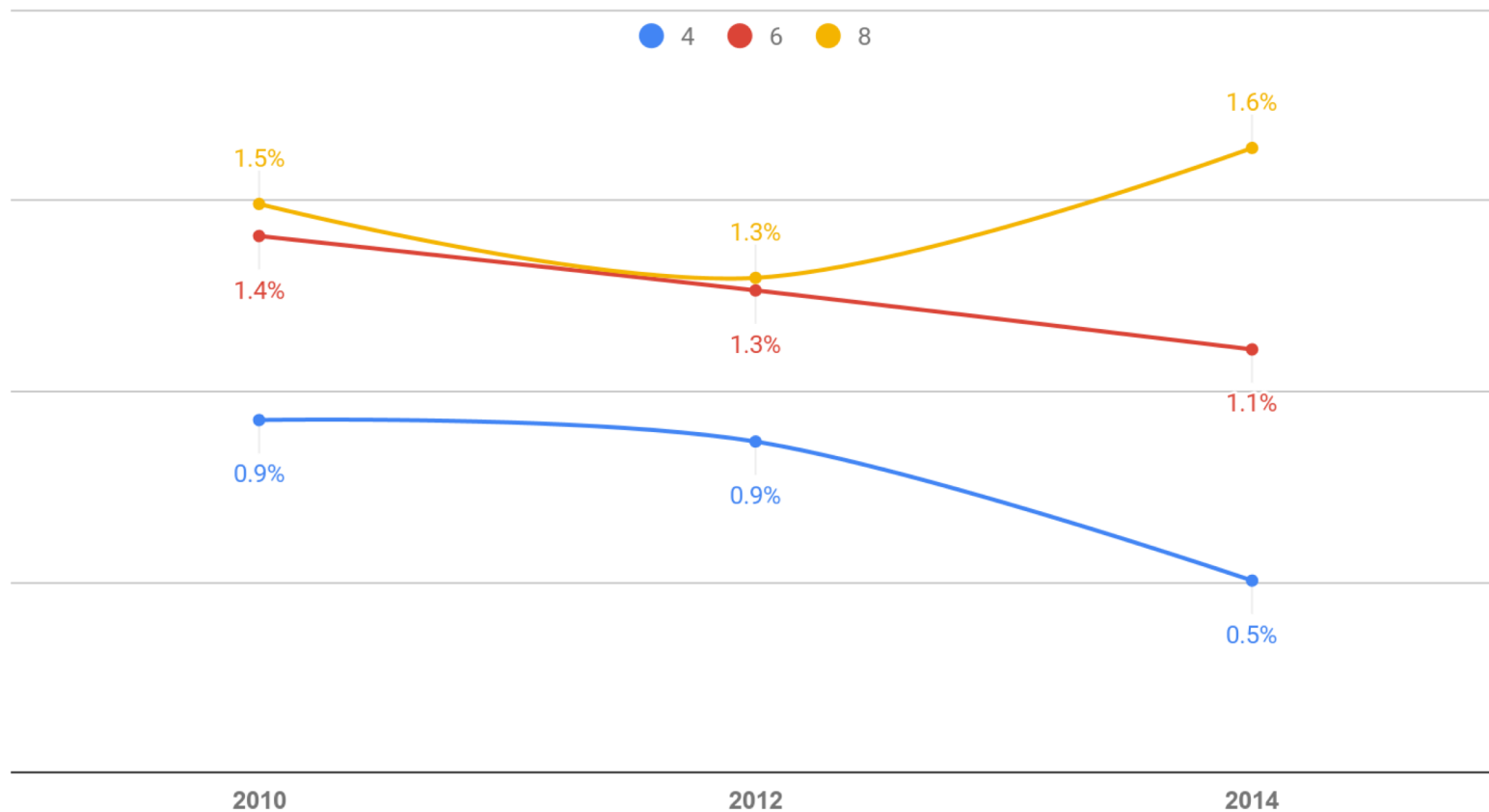


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Monitoring Occurrence:

Prevalence Rates by Age





Monitoring Occurrence:

- Approximately 1/3 of children with ASD are not identified until after age eight
- Delayed identification may be related to
 - ASD Severity
 - Race/Ethnicity
 - Degree of Urbanicity
 - Socioeconomic Status
- More accurate prevalence rates are closer to **1 in 50** by age 16



Reducing the Age of First Diagnosis:

- Current age of first Dx is 52 months
- Can be Dx'd as early as 18 months
- Only 44% of children Dx'd with ASD were screen for ASD using an M-CHAT R/F
- The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT R/F) screener is used for toddlers between 16 and 30 months of age to assess risk for ASD



Reducing the Age of First Diagnosis:

- Two Initiatives:
 - M-CHAT R/F available through Help Me Grow Utah coming in the Fall
 - M-CHAT R/F initiative with the Autism Spectrum Disorder Clinic

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Reducing the Age of First Diagnosis:

- M-CHAT-R/F available through Help Me Grow Utah coming the fall.

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.
© 1999 Diana Robins, Deborah Fein, & Marianne Barton

If you point at something across the room, does your child look at it? (**For Example**, if you point at a toy or an animal, does your child look at the toy or animal?)

Yes

No

Have you ever wondered if your child might be deaf?

Yes

No

Does your child play pretend or make-believe? (**For Example**, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)

Yes

No

Does your child like climbing on things? (**For Example**, furniture, playground, equipment, or



Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

M-CHAT-R™ © 2009 Diana Robins, Deborah Fein, & Marianne Barton

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Yes

No



HELP ME GROW **UTAH**

Thank you for taking time to complete this screening!

A Parent Support Specialist will contact you with the results in the next two weeks. Results are best discussed over the phone, but if we are unable to reach you we will contact you another way.

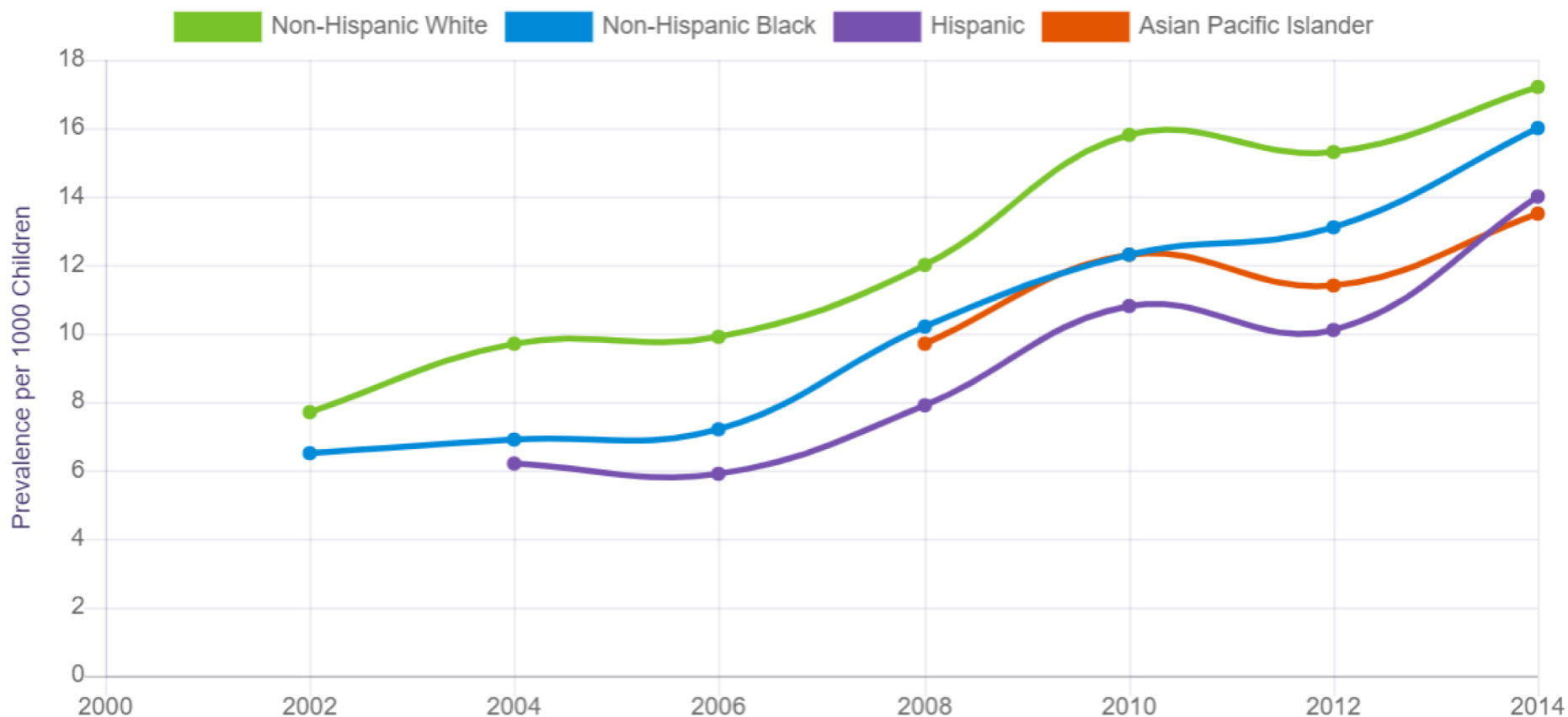
You are welcome to contact us @ 801.691.5322

When using Help Me Grow Utah (HMGU), basic information is collected about your family and the services provided. With your permission, HMGU communicates with your family's physician(s) and other providers. HMGU also teams with other entities to share data that gives an overall view of how Utah's children are doing. With some places, your personal information will be shared only during data transfer. In all cases it will be removed before use in research, community coordination or to inform future decision making. By using HMGU services, you are consenting to the sharing of your information unless you ask otherwise. For more details, visit: helpmegrowutah.org or talk to a HMGU staff member.

Autism System Development



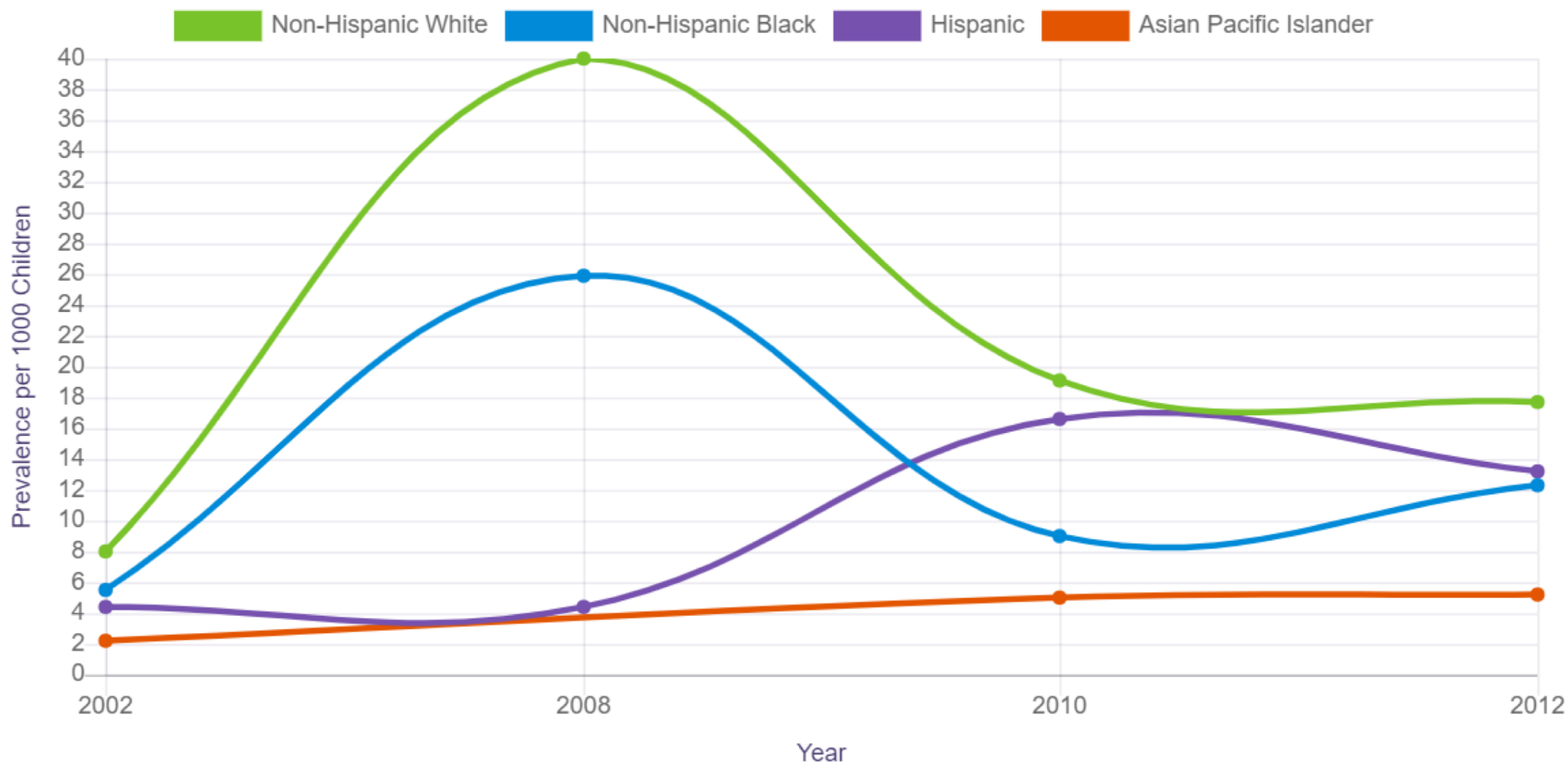
Show ADDM prevalence estimates* by race/ethnicity for: U.S. or Total+ ▼



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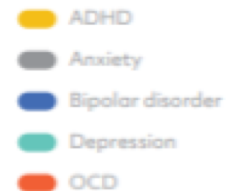


Show ADDM prevalence estimates* by race/ethnicity for:

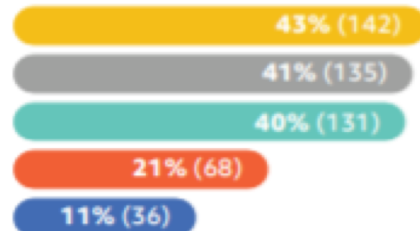


Mental health

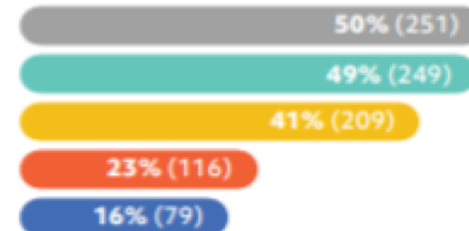
Anxiety and depression were the most common concerns reported by independent adults with autism enrolled in SPARK. Other studies also report high levels of anxiety and depression in adults with autism.



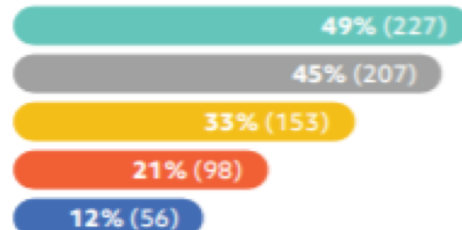
Age 18 - 24 (n=331)



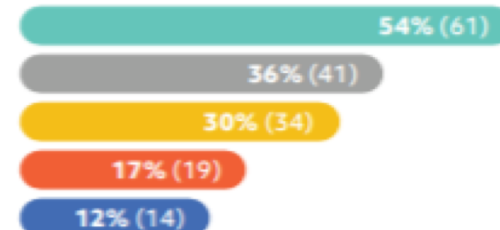
Age 25 - 34 (n=505)



Age 35 - 54 (n=465)



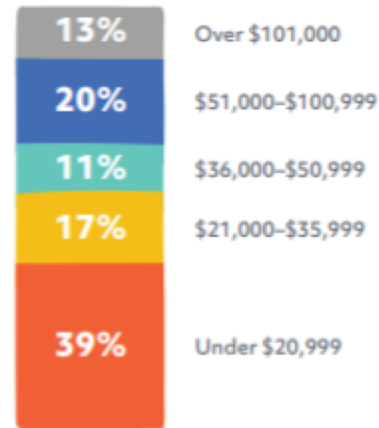
Age 55+ (n=114)



Lifestyle

Household income

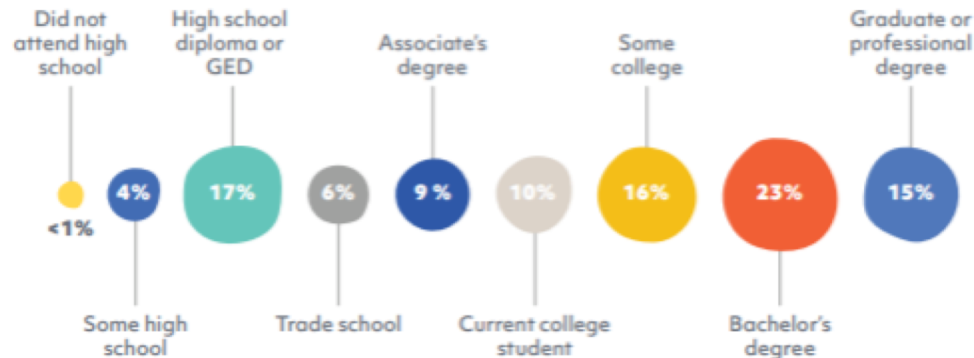
Employment income (e.g., salaries, wages, etc.) reported by independent adults with autism enrolled in SPARK is lower than the national average for employed people. Other autism studies have found this as well.



Education

More than three-quarters of independent adults with autism enrolled in SPARK have a degree or training beyond high school, including the 10%

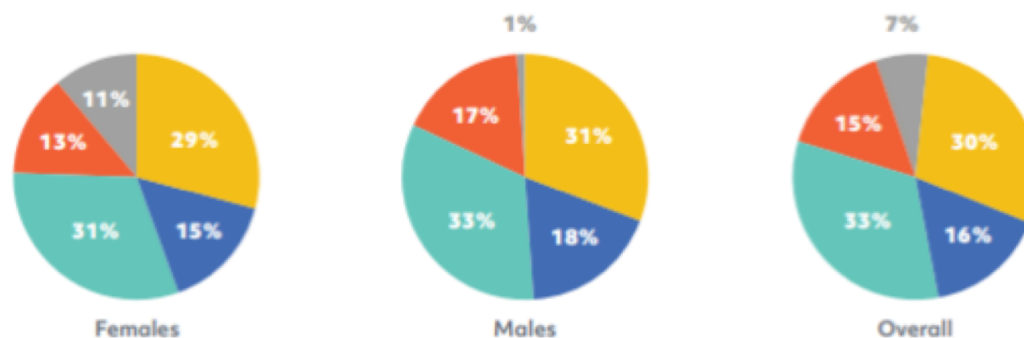
of participants who are currently enrolled in college.



Employment

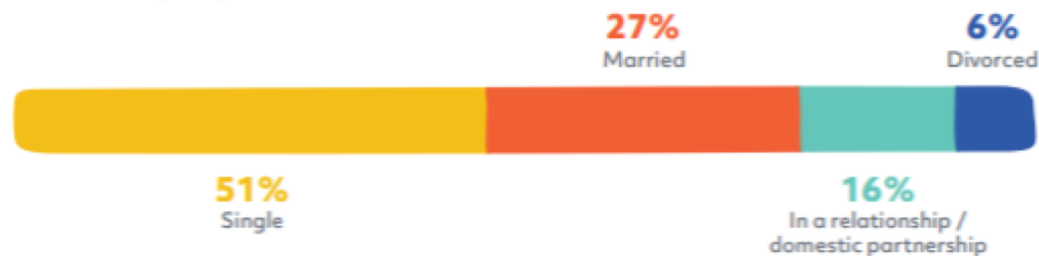
Nearly half of the independent adults with autism enrolled in SPARK are employed either full time or part time. The unemployment rate among independent adults with autism enrolled in SPARK — that is, the proportion who are seeking but have not found paid work — is 22%. More female than male participants report being full-time caretakers.

- Employed full time
- Employed part time
- Unable to work, unemployed or retired
- Student
- Full-time caretaker

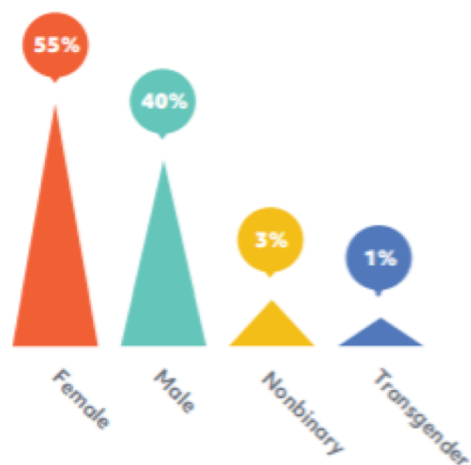


Marital status

Just over half the independent adults with autism enrolled in SPARK are single. Many are married or in a relationship. Only 6% are divorced.



Gender & sexuality

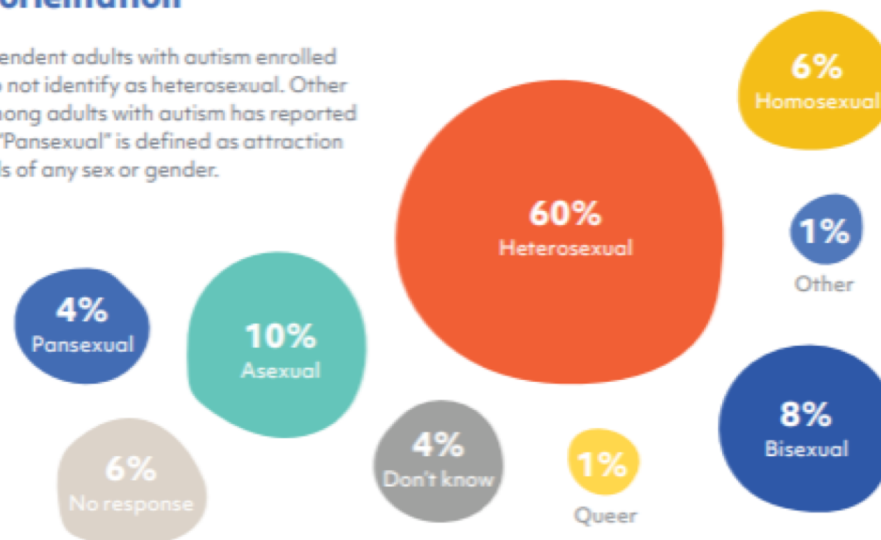


Gender identity

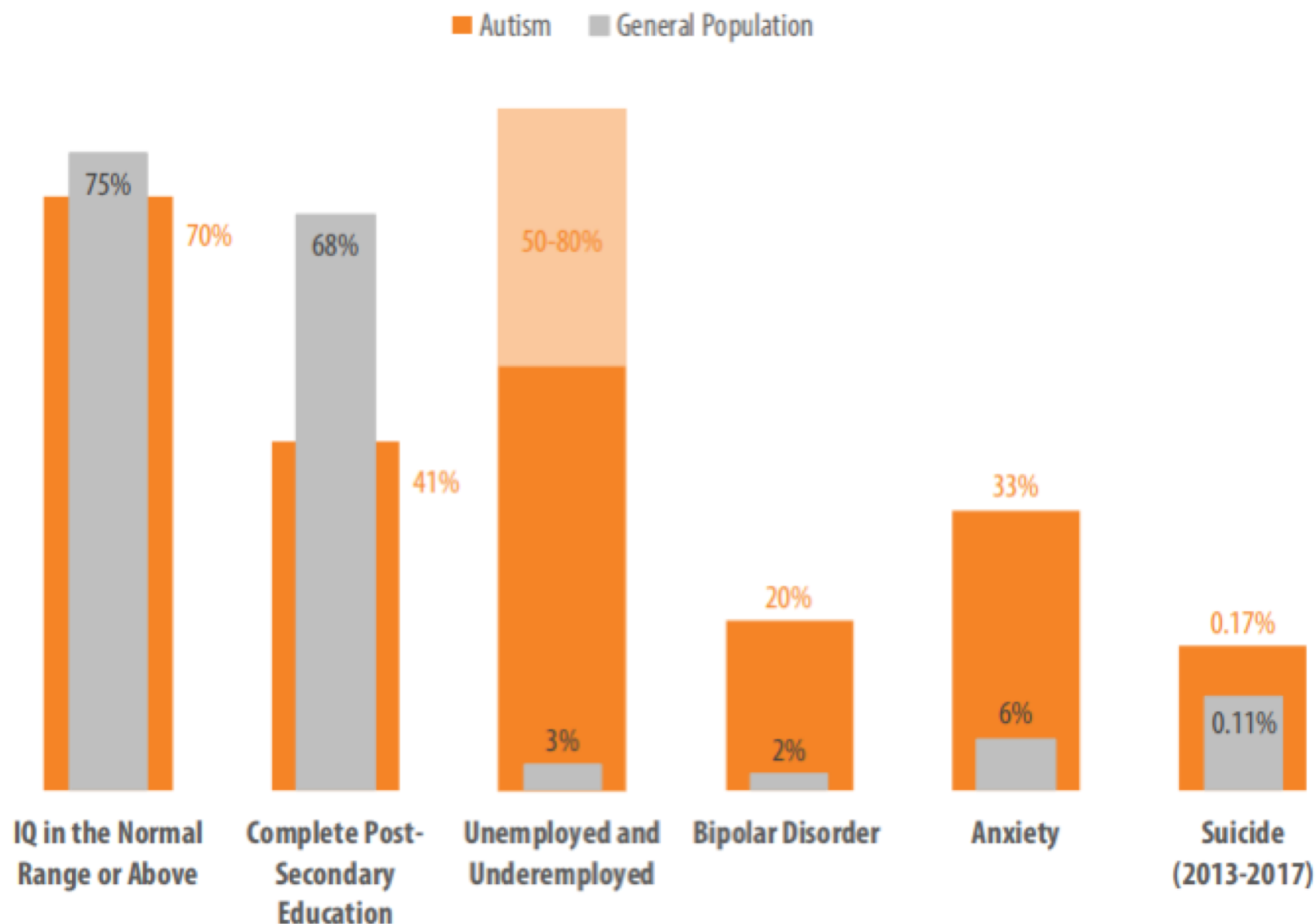
When asked about gender, 3% of independent adults with autism enrolled in SPARK reported a gender other than male or female, and 1% reported being transgender. Other studies have indicated that gender dysphoria — defined as a conflict between the physical or assigned gender and the gender with which the person identifies — is higher among individuals with autism than it is in the population at large.

Sexual orientation

Many independent adults with autism enrolled in SPARK do not identify as heterosexual. Other research among adults with autism has reported this as well. "Pansexual" is defined as attraction to individuals of any sex or gender.



Characteristics of Individuals With Autism in Utah



Sources: Utah Registry of Autism and Developmental Disabilities, University of Utah, Utah Population Database, Utah Office of the Medical Examiner, Intermountain Healthcare, Department of Workforce Services, CDC's Utah Autism and Developmental Disabilities Monitoring Network

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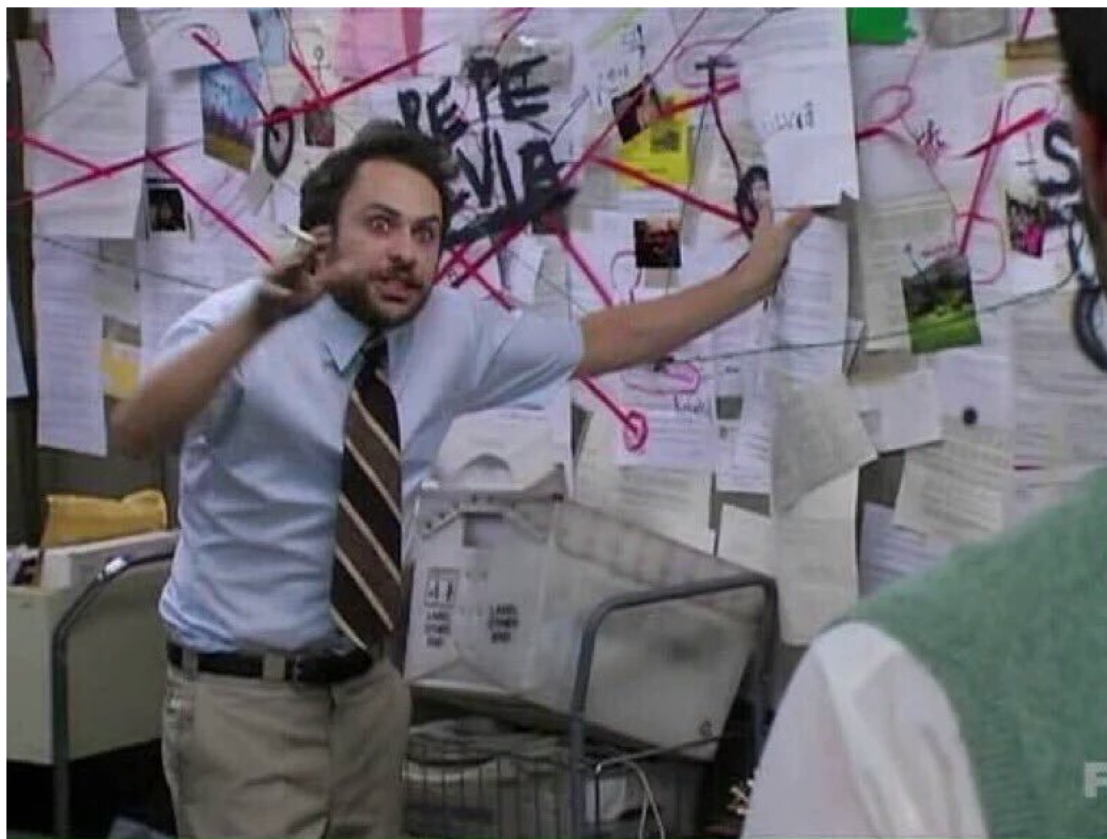
Resources:

- Medical Home Portal:
 - <https://ut.medicalhomeportal.org>
- Autism Systems Development Program:
 - <CSHCN.LINK/Autism>
- Life With:
 - <http://life-with.org/mypath>
- Autism Council of Utah:
 - <AutismCouncilofUtah.org>

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Process for a Diagnosis:



Autism System Development



SB0095

- Requires certain health benefit plans to provide coverage for behavioral health treatment for individuals with an autism spectrum disorder;
- Prohibits certain health benefit plans from limiting hours of treatment for autism spectrum disorder; and
- Removes a provision that allows the commissioner to waive the requirement that a health benefit plan cover the diagnosis and treatment of autism spectrum disorder.

<https://le.utah.gov/~2019/bills/static/SB0095.html>



Facilitating Research:

- Labor Induction and Augmentation:

- Intermountain Health Care and URADD collaborated on a longitudinal study and determined that labor induction and/or augmentation during childbirth are **not** associated with increased risk of Autism.

- Suicide and Autism:

- URADD conducted a first of its kind, 20-year study, and determined that suicide risk is higher in individuals with Autism, especially among females with Autism (who are at a three-times-higher risk of suicide than the general public) and that suicide rates among individuals with Autism are rising faster than in the general public.

- Inflammation During Pregnancy and Autism:

- URADD collaborated with the First and Second Trimester Evaluation of Risk (FASTER) study at the University of Utah and Intermountain Health Care to determine if inflammation during the 2nd trimester is associated with a greater risk of Autism.
- These findings should be published in the near future.

THANK YOU!



Colin Kingsbury
ASDP Program Manager, Children
with Special Healthcare Needs,
Utah Department of Health

For more information, please visit
our website at
<https://health.utah.gov/cshcn/>



The screenshot shows the website for the Utah Department of Health's Children With Special Health Care Needs (CSHCN) program. The header includes the Utah Department of Health logo, navigation links for Services, Agencies, and a search bar. The main title is "Children With Special Health Care Needs" with contact information: Phone (801) 584-8284 and Toll Free (800) 829-8200. A navigation menu includes Home, About Us, Programs, Families, Resources, Data, Forms, and Contact Us. The main content area features a banner for the "Baby Watch Early Intervention Program (BWEIP)" with a photo of a family and the text "Support for infants and toddlers with special needs." Below this is a section for "Children with Special Health Care Needs (CSHCN)" describing the mission and listing contact information: (801) 584-8284 Phone, (800) 829-8200 Toll Free, Monday thru Friday - 8 am to 5 pm, and cshcn@utah.gov. There is also a section for "Fostering Healthy Children" with a photo of children and text about the program's mission and contact information. On the right side, there are two additional sections: "Children with Special Health Care Needs (CSHCN)" with contact information and "Newborn Screening" with links for Hearing, Heart, and Heelstick.

utah.gov Services Agencies Search Utah.gov

UTAH DEPARTMENT OF HEALTH

Children With Special Health Care Needs

Phone (801) 584-8284
Toll Free (800) 829-8200

Home About Us Programs Families Resources Data Forms Contact Us

Baby Watch Early Intervention Program (BWEIP)
Support for infants and toddlers with special needs.

Children with Special Health Care Needs (CSHCN)

The mission of CSHCN is to improve the health and quality of life for children with special health care needs, and their families, through early screening and detection, data integration, care coordination, education, intervention, and transition.

Fostering Healthy Children

The mission of the Fostering Healthy Children Program is to facilitate and advocate for excellence in medical, dental, mental health, and overall wellbeing for children in Utah's foster care system.

Our team of registered nurses are co-located with Division of Child and Family services caseworkers in offices across all of Utah and work in partnership with them to ensure that all foster children receive the healthcare they require.

For more information, [click here](#)

Children with Special Health Care Needs (CSHCN)

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Newborn Screening

Hearing
Early Hearing Detection and Intervention (EHD)

Heart
Critical Congenital Heart Defect (CCHD)

Heelstick
Newborn Blood Spot

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