

The Utah Autism Initiative's state plan to improve outcomes for individuals with Autism Spectrum Disorder (ASD) and Developmental Disorders (DD) 2017-2022

Outcomes

Contributors:

The Utah Autism Initiative (UAI), The Autism Council of Utah (ACU), The Utah Department of Health and Human Services (DHHS), The Office of Children with Special Health Care Needs (CSHCN), the Division of Services for People with Disabilities (DSPD), Medicaid, Intermountain Health (IH), Utah State University Center for Persons with Disabilities, Utah Family Voices (UFV), Utah Parent Center (UPC), The University of Utah Department of Pediatrics, The University of Utah Department of Psychiatry, The Melisa Nellesen Center for Autism at Utah Valley University, Columbus Community Center, ScenicView Academy, Valley Behavioral Health (VBH), The Utah Registry of Autism and Developmental Disabilities (URADD), Parents, Self-Advocates and many more.

History:

In 2008, a study by the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) estimated that Utah had one of the highest prevalence rates of individuals with autism in the nation. As a result, in 2009, a group of professionals, organizations, agencies, and parents worked together to create a plan for Autism Spectrum Disorder and Developmental Disabilities (ASD/DD) in the state of Utah. Initially, the group proposed 17 recommendations to address ASD/DD. The plan was revised in 2017 focusing on 6 areas: coordination of effort, services, service access in rural communities, training, person and family-centeredness, and research.

Over the last 5 years, this plan has been used to guide the state of Utah in improving services for individuals with autism. The plan has also been used to get funding and improve policies. Utah is now a leader in the country in providing services for people with autism.

Area 1: coordination of effort

Background: The coordination of ASD/DD related services and support is not systemic and often relies on personal relationships, rather than on established policy and system structure.

Parents and family members of children and youth diagnosed with ASD and DD are often unaware of the variety of resources available. Due to unclear policy expectations and lack of system structure, a warm handoff from one agency to another (e.g., early intervention to special education, special education to adult services) is nonexistent.

Objective #1: Maintain an Autism and Developmental Disabilities Systems coordinator.

Activity: Orient the ASD/DD coordinator to the range of services/resources throughout the state. This individual should document these services thoroughly and update them over time.

Outcome: The Autism Systems Development Program at UDHHS is a critical component of maintaining up-to-date information and bridging the gap between providers, agencies, and parents.

Objective #2: Improve communication and collaboration between programs and services along the continuum.

Activities: Establish collaborative agreements between state agencies and organizations focused on social and mental health, early intervention, education, habilitation, and employment.

Outcome: Coordination and collaboration between state agencies has improved significantly. The Utah Autism Initiative quarterly meeting brings together over 15 organizations to encourage coordination and collaboration, and several smaller committees and groups of professionals, providers, and parents have been formed to collaborate and educate regarding ongoing issues.

Utah DHHS has several agreements in place with service providers to improve social and mental health, early intervention, education, habilitation, and employment services for adults with ASD. Additionally, data-sharing agreements are in place between multiple agencies to allow the state to make data-driven decisions.

Objective #3: Reduce barriers in linking individuals diagnosed with ASD/DD to treatment/therapy providers.

Activity: Compile a list of ASD/DD Practitioners/Providers in Utah, the areas of the state they serve, wait times, accepted forms of payment, age ranges served, and the languages they speak.

Outcome: The CSHCN [autism evaluation](#) and [ABA providers](#) lists are downloaded at an average rate of ~5,000 downloads per month. Additionally, these lists have expanded to include 35 autism evaluation specialists (20 in 2018) and 45 Applied Behavior Analysis (ABA) providers (21 in 2018).

Contributors:

The Medical Home Portal, The Utah Parent Center, DHHS Integrated Services Program, The Autism Council of Utah, and many others.

Area 2: services

Background: Early screening for ASD and DD is inconsistently administered or not at all. Healthcare practitioners may be hesitant to provide early diagnosis. This can create a delay in care for the mental and emotional well-being of families of children with ASD and DD.

Along the Wasatch Front, there are long waitlists for evaluation/diagnostic services and limited access to treatment options.

Pediatricians and family care physicians are not systematically trained to assess, diagnose, or treat individuals with ASD or DD. Knowledge and experience of these practitioners vary, as well as the quality of diagnostics.

Funding for the full array of services and supports for individuals with ASD and DD is not available to all who need it.

Day programs to meet the needs of individuals with more severe/profound manifestations of ASD behavior are limited and may not provide an environment for the individual's best quality of life. In addition, while some employers provide supported employment placements for individuals with mild to moderate autism, there is a need for many more placements.

Housing options for adults with ASD/DD are not readily available. Individuals with ASD/DD should have choices for housing that meet their needs, whether it is a group home setting in the community or a more structured environment such as Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID).

Evaluation and treatment options for ASD are limited and their areas of expertise, target patients, payment policies, and contact information may not be well advertised.

Objective #1: Reduce barriers to screening services along the Wasatch Front.

Activity: Target pediatricians, early intervention, local health departments, and health care practitioners for ongoing The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT R/F) training and usage.

Outcomes: In 2017 the Autism Council of Utah distributed ASD resource information to pediatrician offices throughout the state for distribution to families.

In order to reach families without a primary care physician, Help Me Grow Utah started offering the M-CHAT R/F to their clients in the spring of 2019. In 2022, Help Me Grow Utah screened 176 children for ASD and referred 233 children to appropriate services. The M-CHAT R/F is designed for children 16 to 30 months of age. If an M-CHAT R/F is properly administered, these children can get appropriate Part-C and Part-B services. If this screener leads to appropriate testing and diagnosis, these children can enter school with an appropriate classification (General Education, 503, or Special Education). Additionally, the University Developmental Assessment Clinic (UDAC) and Intermountain Health (IH) have undertaken a project to screen for ASD using the Parent's Observations of Social Interactions (POSI) at 18, 24, and 30-month visits, and have seen dramatic increases in screening over the last year.

Objective #2: Target funding for critical services and supports.

Activities:

- Coordinate agency program and funding needs in a cost-effective manner and provide the most needed services.
- Prioritize existing and unmet needs for ASD/DD services in Utah.
- Apply for federal and state funding.
- Identify additional funding mechanisms or opportunities.
- Seek to enhance coverage for ASD/DD services through private and public insurance.
- Ensure that children, youth, and adults diagnosed with ASD/DD have full access to the continuum of effective services and therapies that will improve individual outcomes.

Outcomes:

The Carson Smith Special Needs Scholarship was passed in legislation giving all pre-school, and school-aged children, covered by the Individuals with Disabilities Education Act (IDEA), a scholarship based on the weighted pupil unit to attend a private school. There are currently 49 eligible schools and over 1,000 children on the scholarship.

In 2014, the Utah State Legislature passed SB57, requiring certain parts of the state-regulated health insurance market to cover autism. Subsequently, the age cap for these services has been removed for private insurance and Medicaid.

In 2022, The Adult Autism Treatment Account (AATA) went into effect. The AATA provides additional funding for services to individuals with ASD who require significant support. Forty-one clients have been funded to help improve their adaptive, behavioral, and communication abilities.

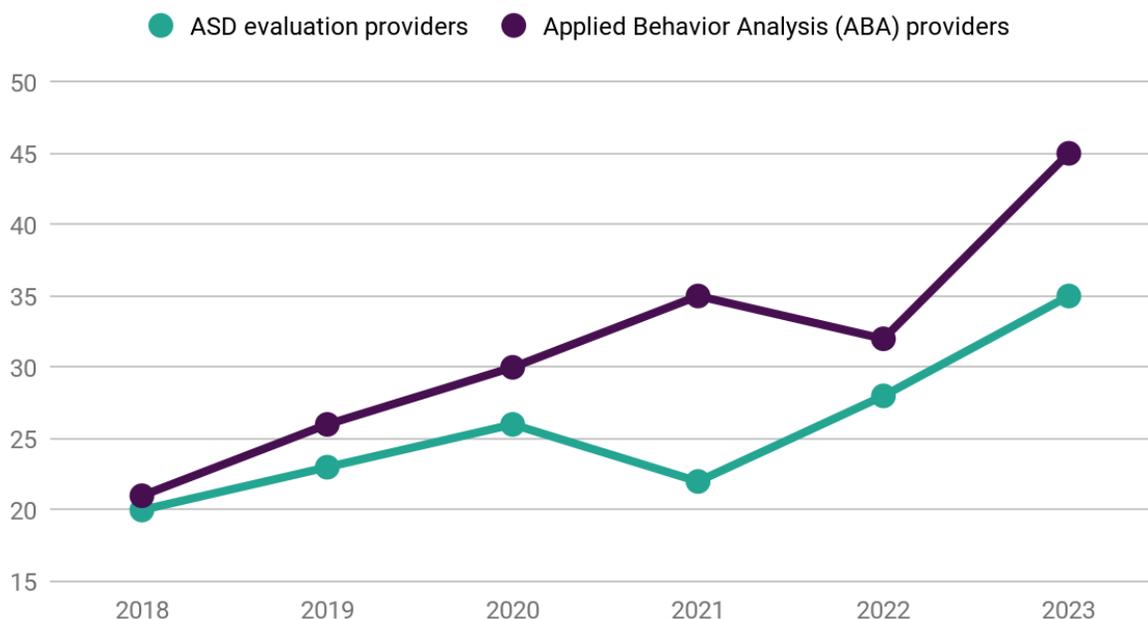
Objective #3: Identify and expand a variety of specialists in health and education disciplines who serve ASD/DD.

Activities:

- Conduct training needs assessment across service disciplines.
- Encourage providers to expand their existing service areas.
- Encourage training that promotes a culturally competent/appropriate workforce.

Outcomes: Since 2018, the number of ASD evaluation and ABA providers has increased statewide.

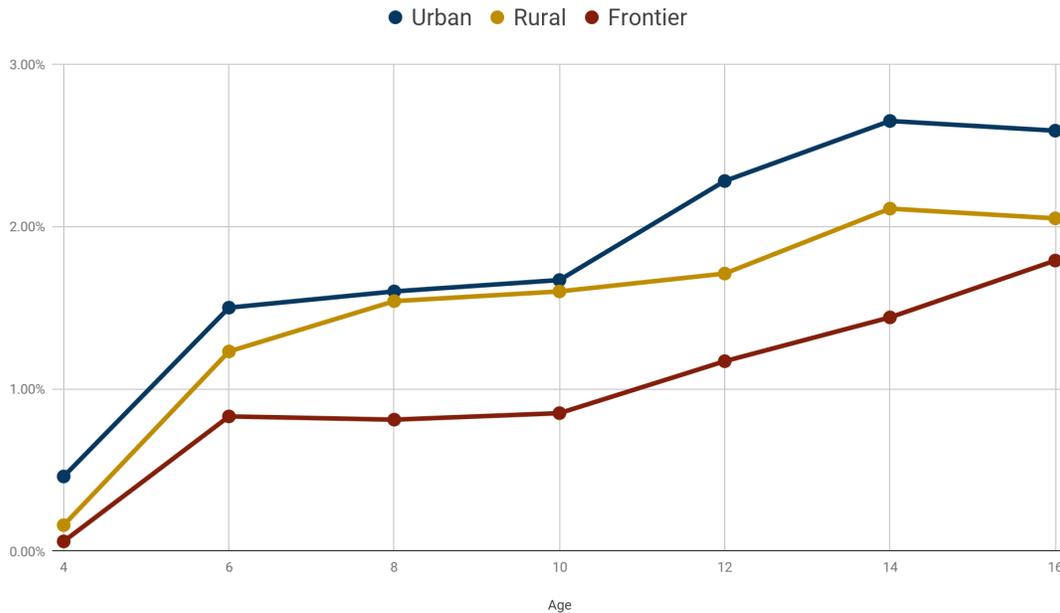
ASD evaluation and ABA providers



Although the number of ASD providers has increased, the discrepancy between services in urban counties, rural, and frontier counties remains substantial. While 91% of ABA providers serve urban counties, only 27% serve rural counties and only 16% serve frontier counties, with many rural and frontier providers having no access to an ASD assessment or ABA.

As shown in the graph below, identification of ASD in rural and frontier areas is lacking, with many individuals missing critical windows for early intervention.

Prevalence Estimates - Urban, Rural and Frontier



Urban = Cache, Weber, Davis, SLC and Utah, Rural = Box Elder, Carbon, Iron, Morgan, Sanpete, Sevier, Summit, Tooele, Uintah, Wasatch, Washington, Frontier = Beaver, Daggett, Duchesne, Emery, Garfield, Grand, Juab, Kane, Millard, Piute, Rich, San Juan, Wayne

Objective #4: Strive to increase the quality and quantity of day programs to meet the needs of people with more severe or profound manifestations of ASD/DD behavior.

Activities: Encourage the increase in the quality and quantity of day programs that meet the needs of people with more severe or profound manifestations of ASD/DD behavior.

Outcomes: The Adult Autism Center of Lifetime Learning (AAC), a first of its kind in Utah, was built in 2020 by Valley Behavioral Health. The AAC utilizes strategies of ABA for providing treatment. Additionally, as part of the AATA, several existing day programs have been able to dramatically improve the quality of their services for individuals with severe or profound manifestations of ASD/DD behavior.

Objective #5: Develop and implement a system of trained behavior specialists who can continually provide support to individuals with ASD/DD.

Activities:

- Facilitate the development of a statewide group of behavior specialists in human service agencies and organizations. These specialists can serve as a technical assistance resource to public and private providers of social and health care services, assisting in the implementation and evaluation of positive behavioral support plans. Training of this group and those to whom they provide assistance would be an ongoing need.

- Develop a statewide network of appropriate options emphasizing education, leisure education and socialization, and employment for adolescents and adults diagnosed with ASD/DD. This should include a continuum of options based on individual support needs.
- Improve ASD/DD outcomes across adult systems through access to and availability of behavior management training, including trauma-informed behavior management training.
- Develop and implement training for individuals with ASD/DD and their families on relevant topics.

Outcome: While the number of Board Certified Behavior Analysts (BCBA) statewide has increased, there is still only 1 BCBA for every 40 individuals with ASD (under 21). Transportation, waitlists, insurance coverage, and reimbursement rates remain barriers to these services. Many providers have different waitlists according to insurance coverage based on reimbursement and can choose clients with less intense needs. The University of Utah, College of Education, and the Melisa Nellesen Center for Autism at Utah Valley University (UVU) have been working to increase the number of BCBAs in the State, and UVU has conducted training for BCBAs to improve ABA practices statewide for individuals with profound ASD.

Objective #6: Increase the availability of screening for emotional and mental health stability for the adult population.

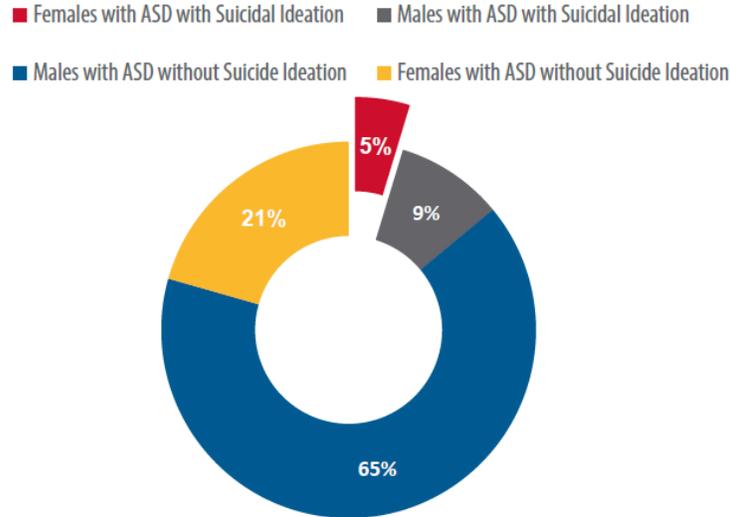
Activities: Work with health care providers to develop screening for emotional and mental health stability in adults with ASD/DD.

Outcome: The Sources of Distress, developed by Dr. Deborah Bilder is now available on the [CSHCN Website free of charge](#). The Sources of Distress is a computerized tool developed for parents and professional caregivers of children and adults with severe neurodevelopmental disabilities. This tool uses a computerized branching logic algorithm to identify potential underlying treatment targets for irritability and agitation that may otherwise have been unrecognized or insufficiently treated. As of 2021, over 200 individuals with ASD have received support from the Sources of Distress, free of charge.

As part of determining the need for emotional and mental health screeners, from 2010–2019, Utah Registry of Autism and Developmental Disabilities (URADD) evaluated characteristics of suicidal ideation from individuals with ASD and found 9% of male and 5% of female individuals with ASD had evidence of suicidal ideation. While the male-to-female ratio for individuals with ASD is 3.6 to one, 5% of females with ASD made up more than one-third of all individuals (14%) with ASD combined with suicidal ideation (Figure 1 below).

Percentage of Suicidal Ideation with Autism Spectrum Disorder in Utah, by Gender, 2010–2019

Figure 1. Males reported more frequent suicidal ideation among those diagnosed with autism spectrum disorder.

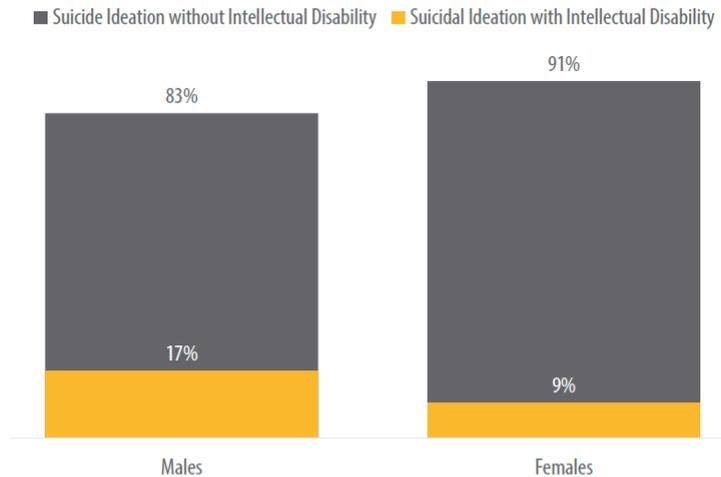


Source: The Utah Registry of Autism and Developmental Disabilities (URADD)
 Note: Lifetime suicide ideation is from 937 individuals with autism spectrum disorder born in 2002.

Among Individuals with ASD and suicide ideation, 17% of males and 9% of females had evidence of intellectual disability (Figure 2 below).

Percentage of Suicide Ideation with Autism Spectrum Disorder, by Intellectual Disability Status and Gender 2002-2018

Figure 2. Males and individuals with no intellectual disabilities reported more frequent suicidal ideation among those diagnosed with autism spectrum disorder.

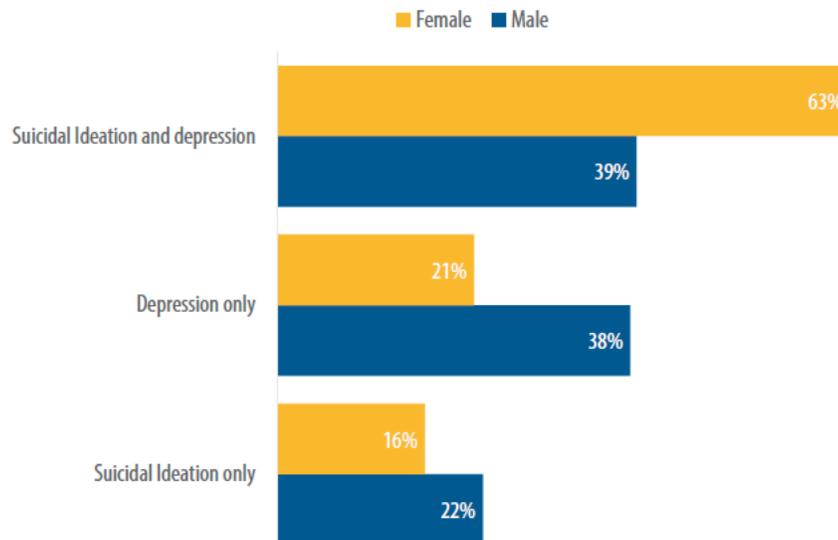


Source: The Utah Registry of Autism and Developmental Disabilities (URADD)
 Note: Lifetime suicide ideation is from 937 individuals with autism spectrum disorder born in 2002.44

Nearly half of all individuals (91 in 199) with ASD and depression also reported having suicidal ideation. Most females (63%) reported the highest percentage of depression with suicidal ideation compared with males (39%). While males reported having higher percentages of only depression (38%) and suicidal ideation without depression (22%), depression with suicidal ideation was the most common reported issue in both males and females (Figure 3 below).

Percentage of Suicidal Ideation and Depression With Autism Spectrum Disorder, by Gender 2010–2019

Figure 3. Females reported the highest percentage of suicide ideation with depression..



Source: The Utah Registry of Autism and Developmental Disabilities (URADD)

Note: Lifetime suicide ideation is from 937 individuals with autism spectrum disorder born in 2002.

Suicide and suicidal ideation are important characteristics to understand in regard to individuals with ASD, and more accurate instruments of suicidal ideation need to be developed.

Resources

- 988
- 24-hour Suicide Prevention Lifeline, 1-800-273-TALK (8255)
- Utah Suicide Prevention Coalition Utahsuicideprevention.org
- The SafeUT <https://safeut.org/>
- Live On <https://liveonutah.org/>

Objective #7: Increase independent living options for adults with ASD/DD.

Activities:

- Support education to individuals with ASD/DD regarding self-advocacy, independent living skills, community access, behavior counseling, and supported employment.
- Research funding mechanisms that enable adults with ASD/DD to exercise choice and self-determination in their community-based living arrangements.

- Incorporate appropriate opportunities for employment, social and recreational activities, and housing options for adults with ASD/DD.
- Develop a statewide network of appropriate options emphasizing education, meaningful activities and day programs, and employment for adolescents and adults diagnosed with ASD/DD.

Outcomes: Over the last 5 years, many programs have developed and launched programs aimed at improving self-advocacy, independent living skills, community access, behavior counseling, and supported employment for individuals with ASD.

[The Columbus Community Center launched the Hub of Opportunity in 2020.](#) As part of this initiative, the NextWork Columbus Community Center Autism Program reserves ten apartments at the Hub of Opportunity for students who are ready for independent living. The NextWork Academy aims to support well-rounded and thoughtful neurodiverse people by offering tools to cope with a changing post-modern and globalized world, and providing opportunities for integrated and competitive employment, building community, and increasing independence. They encourage our participants to challenge their limits, not limit their challenges.

[ScenicView Academy](#) is a program designed to build the autonomy, competence, and connections of young adults with neurodevelopmental differences. Students become part of a unique community that respects the challenges, strengths, and contributions of each individual while working to develop the skills, responsibility and relationships needed for individuals in a community to live, work, and thrive, together.

[Spectropolis, a program of The Autism Clinic](#) creates a safe and welcoming place for people on the Autism Spectrum and their families to connect through shared interests, activities, and community.

[The Melisa Nellesen Center for Autism at Utah Valley University](#) improves the quality of life for those living and working with ASD by preparing students for professional careers in the field, providing evidence-based services and education, and fostering a community of belonging, with a variety of programs including the Passages transition services. Passages provides support for young adults with ASD during their journey to adulthood. There are currently two options available. First, the Personal Empowerment Program includes access to a series of courses and activities focused on successful transition to adulthood and is available to individuals in the community between the ages of 18- 40. Secondly, the Educational Coaching Program offers personalized support while attending Utah Valley University through regular weekly meetings with a peer, who assists with student-led academic goals.

Although there have been improvements in housing and employment options, the challenges are ongoing for appropriate and affordable housing, and willing community partners for employment.

Area 3: service access in rural communities

Background: Effective services for individuals with ASD and DD are not equally available statewide, particularly in rural and frontier areas. Access to screening, evaluation and diagnostic services, and treatment options are limited outside of the Wasatch Front. Training and technical assistance regarding screening and treating children with ASD/DD is needed in rural communities.

Objective #1: Ensure that training, resources, and services are available in all areas of the state, including rural and remote Utah communities.

Activities:

- Develop technological infrastructure for rural training and treatment (sites, hardware, software, Project Extension for Community Healthcare Outcomes, etc.)
- Facilitate dialogue among third-party payers, including Medicaid and the Children's Health Insurance Program (CHIP), to develop payment policy for evidence-based ASD/DD telehealth services.
- Leverage current telehealth initiatives and emulate programs that have demonstrated proficiency with distance services.
- Encourage the advancement of telehealth capacity for evaluative, diagnostic, treatment and therapy services.
- Encourage service organizations and other agencies to create and provide respite services and resources across the lifespan.

Outcomes: In 2020, CSHCN and the Integrated Services Program purchased telehealth technology. This telehealth technology is available for families in rural communities to use free of charge. Currently, around 58% of ABA providers have a telehealth option, depending on need and insurance coverage.

Objective #2: Reduce barriers for screening services outside of the Wasatch Front.

Activities:

- Target pediatricians, early intervention specialists, and health care practitioners in rural communities for ongoing M-CHAT training and usage.
- Identify and develop screening tools for adolescents and adults with ASD/DD.
- Provide training for ASD/DD screening in person and through telehealth across the state.
- Pilot a screening process with referrals to Up-to-3 Early Intervention program in Cache, Box Elder, and Rich counties.

Outcomes: In 2017 the Autism Council of Utah delivered ASD resource information to pediatrician offices throughout the state.

In 2019, with a grant from the Autism Council of Utah, Help Me Grow Utah started offering the M-CHAT R/F to their clients. In 2022, Help Me Grow Utah screened 176 children for ASD and referred 233 children to appropriate services. The M-CHAT R/F is designed for children 16 to 30 months of age. If an M-CHAT R/F is properly administered, these children can get appropriate Part-C and Part-B services. If this screener leads to appropriate testing and diagnosis, these children can enter school with an appropriate classification (General Education, 504 Plan, or Special Education). Additionally, the University Developmental Assessment Clinic (UDAC) has trained providers throughout the state on the Screening Tool for Autism in Toddlers & Young Children (STAT) and is working with Intermountain Health on using the Parent's Observations of Social Interactions (POSI) to screen for ASD.

Area 4: training

Background: Ongoing training for healthcare providers, public safety staff, including first responders, police, and emergency medical technicians, is needed in order to interact with individuals diagnosed with ASD/DD. Training for the community, businesses, and companies on ASD awareness, acceptance, employment options, and interacting with individuals on the spectrum is needed. Behavior management across a variety of environments is a tremendous need. Trained behavior specialists, who can continually provide support to individuals and their support staff, are a critical need.

Objective #1: Build capacity to provide and support evidence-based training on assessment and treatment services across disciplines with long-term outcome data.

Activities:

- Conduct needs assessment across service disciplines.
- Provide evidence-based training across disciplines.
- Encourage training that promotes a culturally competent/appropriate workforce.

Outcomes: Training is ongoing and available for interested parties.

Objective #2: Seek to create a community standard for ASD and DD education within institutions of higher learning around the state.

Activities:

- Promote an autism endorsement for pre-K through transition educators and encourage enhanced training for paraeducators.
- Investigate endorsement and licensure requirements in other states.

Outcomes: The Utah State Board of Education has an Autism and Significant Cognitive Specialist as a resource for educators throughout the state.

Objective #3: Expand and create training for the community, businesses, and companies on autism awareness, acceptance, employment options, and interacting with individuals on the spectrum.

Activities:

- Develop and implement training for the community, businesses, and companies on how to interact with individuals with ASD/DD.
- Develop and implement training for businesses and companies on the skills individuals with ASD/DD can offer them.

Outcomes: The Autism Council of Utah, the UVU Melisa Nellesen Center, and others, provide training for the community, businesses, and companies upon request.

Objective #4: Expand training to healthcare providers, public safety staff, including first responders, police, emergency medical technicians, and Vocational Rehabilitation (VR) counselors on how to interact with individuals diagnosed with ASD/DD on a statewide level.

Activities:

- Provide ongoing training for first responders, police, emergency medical technicians, and VR counselors on how to interact with individuals with ASD/DD.
- Develop and implement training for healthcare providers to serve adults with ASD/DD.

Outcomes: The Autism Council of Utah developed a curriculum and assisted in passing legislation requiring mandatory yearly law enforcement autism and mental health training. The Autism Council of Utah has distributed over 2,000 sensory bags to first responders statewide. Over 800 officers were trained in 2022, and training is ongoing.

The Utah Attorney General's office provides autism training to officers throughout the state in their simulation platform, VirTra.

The Melisa Nellesen Center for Autism at Utah Valley University continues to work with law enforcement agencies around the state to provide ASD training, including fire and water safety.

Area 5: person and family centeredness

Background: Training for parents and families of children with ASD and DD are limited and inadequate. Parents and families must understand how to provide social and behavioral supports, and to understand how to prepare for the transition from pediatric to adult services.

Family support to assist in the services and program transition process is difficult to obtain. This is a particular concern for middle-income families who lack adequate insurance coverage for psychological services and family support.

The transition from childhood to adulthood is difficult for individuals with ASD and DD. Insurance coverage often excludes services to people with a primary ASD diagnosis and ASD treatments. Mental health diagnoses are common among the ASD/DD population, and services for suicide prevention and substance abuse treatment are not readily available.

Objective #1: Support and expand family-focused resource information and training for families affected by ASD and DD.

Activities:

- Involve appropriate organizations to create and provide families with evidence-based information resources and training.
- Ensure that families of children with ASD/DD are connected with appropriate peer support groups.

Outcomes: The Utah Parent Center and Utah Family Voices provide information and resources to families. The Utah Autism Initiative (UAI) prepared documents for families to show what evidence-based resources are. The Autism Council of Utah and the Medical Home Portal list all resources in the state listed on their websites.

Many agencies and providers offer parent training.

Several Utah parent support groups exist on social media, such as Big MAK's and Utah Autism Support.

Objective #2: Expand the involvement of families and individuals with ASD/DD and advocacy groups in all aspects of the state plan.

Activities:

- Review and collect evidence-based research, contribute to existing information resources, participate in the vetting process, and maintain a shared resource (The Medical Home Portal).
- Evaluate current services to ensure quality.
- Encourage families to be involved.
- Provide training activities that enhance family knowledge and capacity, and increase networking opportunities.

Outcomes: The Utah Parent Center trains parents by hosting workshops and conferences. Resources are available if parents choose to participate. Resources are listed on websites and social media. Parents and self-advocates are included in many committees regarding autism.

Objective #3: Teach, train, and support a child/young adult diagnosed with ASD/DD about transition services.

Activities:

- Develop a statewide network for education, activities, and employment opportunities for adolescents and adults diagnosed with ASD/DD.
- Work with agencies to develop housing options for adolescents and adults with ASD/DD.
- Develop leadership and support group opportunities for youth with ASD/DD, including outreach and awareness.

Outcomes: DHHS' Office of Children with Special Health Care Needs, Intermountain Health and the Utah Parent Center have worked together to improve transition to adulthood services. The Utah Parent Center has the Transition University available on its website. This includes modules on Education, Employment and Daily Living Skills, Self-Determination and Person-Centered Planning, and others.

Objective #4: Provide information for parents on their legally defined roles and responsibilities.

Activities:

- Develop and implement training for parents and families on their role in the transition process.
- Develop and implement training for parents, families, and individuals with ASD/DD regarding legal issues such as guardianship, power of attorney, conservatorship, trusts, and other legal concerns.
- Develop and implement training for parents and families and individuals with ASD/DD regarding adult agency supports and services around employment, housing, postsecondary education, and other services such as day programs, behavioral health counseling, and social activities.
- Encourage policy reform to improve insurance coverage on medical, dental, mental health, and acute care benefits for youth with ASD/DD who are on their parent's health plans.
- Ensure that legally mandated post-school transition services are fully available to youth with ASD/DD.
- Develop resource information and training for families and individuals with ASD/DD regarding issues such as maturation, sexuality, social roles, dating, and rights that transfer at age of majority.

Outcomes: Utah Parent Center provides information on guardianship, supported decision-making, and social security applications through workshops, office, staff, and website information. The Autism Council of Utah initiated legislation that would reduce the fee for parents applying for guardianship from \$300 to \$45. Additionally, individuals who are able to make choices about their lives with little assistance can apply for Supported Decision Making guardianship.

Insurance coverage has been expanded for individuals with autism for medical, dental and mental health concerns.

UVU and ScenicView Academy have developed conferences and workshops to address issues such as maturation, sexuality, social roles, and dating for families and individuals with ASD/DD,

Objective #5: Educate young adults with ASD/DD on understanding their rights and responsibilities as an adult.

Activities: Provide education to individuals with ASD/DD regarding self-advocacy, independent living skills, health care, community access, behavior counseling, mental health, employment, and post-secondary education.

Outcomes: As part of the Utah Parent Center Transition University individuals with ASD/DD have access to information via multiple mediums.

Area 6: research

Background: URADD has released ADDM-based prevalence estimates for 8-year-old children in 2002, 2008, 2010, and 2012 and for 4-year-old children in 2010 and 2012.

URADD has published prevalence estimates based on community identification of ASD for 8-year-olds in 2002, 2004, 2006, 2008, and 2010 and for 4 and 6-year-olds in 2004, 2006, 2008, and 2010. Preliminary estimates of the prevalence of ASD in Utah are available based on community identification.

Objective #1: Continue to conduct ASD/DD related surveillance and research, including epidemiologic studies.

Activities:

- Expand URADD's surveillance efforts statewide by May 2017.
- Monitor improvement in families' access to ASD/DD screening, referral, diagnosis and eligibility determination, services and treatment, and care coordination.
- Within URADD, children with an ASD/DD positive screen will be linked with assessment, diagnostic, and treatment service data.
- Improve understanding of ASD/DD including, trends, disparities, and risk factors.

Outcomes:

Since 2018, URADD has dramatically expanded its surveillance efforts to include statewide ASD prevalence estimates for 3-18-year-olds.

Additionally, URADD has provided valuable data on access to ASD screening, diagnosis and eligibility determination, with data indicating that Utah children with ASD are frequently missed, especially in rural and frontier counties. Only ~50% of children with ASD are identified by age 4.

Current trends indicate that children with ASD are underdiagnosed and misdiagnosed. For every 2 children identified with ASD who were age 4, there was 1 child who was suspected but not confirmed to have ASD, leading to a delay in a formal diagnosis for those children.

Objective #2: Continue to build research infrastructure and collaborations across disciplines and institutions to maximize information originating from ASD/DD-based research studies.

Activities:

- Identify and include ASD researchers who are external to URADD's scope and volume of work.
- Develop a mechanism for tracking and documenting Utah-based ASD/DD research that is conducted external to URADD.
- Seek federal and foundation-based funding to support surveillance, epidemiological, and translational research projects.

Outcomes:

URADD has worked with researchers from a wide variety of backgrounds to improve its scope of work and has received multiple grants to improve the occurrence and timeliness of data. Since 2018, URADD has contributed to the publication of 18 peer-reviewed publications. A full list can be found here: <https://medicine.utah.edu/psychiatry/research/labs/uradd/publications>

Summary:

In 2009, the Utah Autism Initiative (UAI) work groups recognized the needs of Utahns with ASD and began developing recommendations for the state. The UAI collaborated on a plan to improve the quality of life for people who have ASD/DD by assessing the current landscape, making a plan, and filling the gaps. In 2017, the UAI conducted a major review and overhaul of the 2009 plan and, with the help of many community partners, has used the 2017 plan to shape the future of ASD/DD in Utah.

While many great strides have been made to increase service capacity for children, and adult services have improved, there are still gaps in services and accessibility throughout the state.

Long wait lists contribute to delays in services causing families to miss crucial developmental windows, and lose out on needed support. More funding for service accessibility, affordable and accessible housing, employment options, trained medical professionals, and appropriate reimbursement rates are needed.

As we move forward the Utah Autism Initiative will continue to track deficits and improvements. This 2023 update will allow us to celebrate our accomplishments and continue to move forward in a meaningful way.

Current Statement of Need:

Utah's estimated prevalence of ASD among 8-year-old children continued to increase from 2.2% in 2018 to 2.5% in 2020.

Data suggests that many 4-year-old children in Utah continue to experience challenges accessing assessments for ASD, with less than one-half of children with ASD receiving a diagnosis of ASD by age 4.

Identification of ASD among children from lower socioeconomic backgrounds has improved. This shows improved access to diagnostic and treatment services across the socioeconomic spectrum. However, the identification of children and youth in rural and frontier counties continues to lag behind, with up to 50% of children with ASD being missed in frontier counties.

Not just ASD, in Utah an individual with ASD generally has 4.6 other diagnoses.

- ADHD: 48%
- Anxiety: 45%
- Depression: 20%
- Intellectual Disability: 29%
- Seizure Disorder: 10%

During the last 20 years, the risk of suicide death for individuals with ASD steadily increased among people ages 5–30 years old. These individuals were more than twice as likely to die by suicide than people ages 5–30 years old without ASD. Females with ASD are more than three times as likely to die from suicide as females without ASD.

2024 Plan Areas of Focus:

Ages Groups

- Screening
 - Level 1
 - Level 2
 - Level 3
- Evaluation
 - Level 1
 - Level 2
 - Level 3
- Services
 - Level 1
 - Level 2
 - Level 3

- **Adulthood**
 - Level 1
 - Level 2
 - Level 3