

Utah's State Plan for Improving  
Outcomes for Individuals with Autism  
Spectrum Disorder (ASD) and  
Developmental Disorders (DD)

2017

## Purpose:

The prevalence of Autism Spectrum Disorder (ASD) has grown dramatically in the past decade. While there are many reasons for the rapid growth in this diagnosis, none have demonstrated a clear cause and effect relationship. Regardless, with the rapidly increasing numbers, there is a critical need to understand issues related to assessment; early diagnosis; services for toddlers, children, youth and adults with ASD, and their families; financing of the range of necessary services and supports; and training for pre-service and practicing professionals in healthcare, education, employment and community-based settings.

Recent data suggest that Utah's experience mirrors the national trends in ASD prevalence. An April 2016 surveillance report<sup>1</sup> by the Centers for Disease Control and Prevention (CDC) indicates that for the reporting year 2012, ASD prevalence among 8-year-old Utah males was the second highest in the U.S. (27.7 per 1000) and third highest prevalence overall (17.3 per 1000 males and females). While the national ratio of males to females is 4.5:1, the Utah ratio is 4.3:1. Overall, non-Hispanic white children have a higher prevalence when compared to other race/ethnicities which are believed to be due to awareness and accessibility to ASD services. In regards to the public school system, 74% of children diagnosed with ASD were enrolled in a special education program in the U.S.; with Utah having a 55% enrollment rate.

In Utah, over the past five years, there have been several entities engaging in statewide efforts to address the myriad issues related to autism. Non-profit groups such as the Autism Council of Utah (ACU) and the Utah Department of Health's Utah Autism Initiative (UAI) are among the most visible examples. Each is attempting to define the issues, identify needs, and recommend consensus-based courses of action to a variety of audiences in Utah including state and local education agencies, health care practitioners, the state legislature, mental health providers, public safety officers, and so on. Nationally, the U.S. Centers for Disease Control and Prevention sponsored two regional ASD summit meetings that enabled state partners to conduct needs analyses and develop recommendations for public and private action with respect to improving the outcomes for children, youth, and adults who are diagnosed on the autism spectrum.

A number of findings or needs were categorized into the following six areas: Coordination of Effort, Services, Service Access in Rural Communities, Training, Person and Family Centeredness, and Research. The following recommendations were suggested and serve as the basis for Utah's State Plan. As funding becomes available for ASD and DD related initiatives, any one or combination of major partners may use the data from this document to serve as an evidence-based foundation for ASD and DD training, research or services.

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1. Retrieved June 09, 2016 from <http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm>

# Area 1: Coordination of Effort

## Background:

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

Due to unclear policy expectations, knowledge of available resources, and system structure, the handoff from one agency to another (e.g., early intervention to special education, special education to adult services) is often unclear to individuals and their families.

Parents and family members of children and youth diagnosed with ASD and DD are not fully aware of the variety of resources available.

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

### Activities:

- Appoint a State employee as coordinator for ASD and DD Services.
- Orient the ASD/DD Coordinator to the range of services/resources throughout the state who should document these services thoroughly and update over time.

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

### Activities:

- Establish collaborative agreements between state agencies and organizations including social and mental health, early intervention, education, habilitation, and employment.

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

### Activities:

- Improve, update and increase access to the Medical Home Portal for diagnostic and treatment providers.
- Compile a list of ASD and DD Practitioners/Providers in Utah, the areas of the state they serve, wait times, accepted forms of payment and age ranges served.

## 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.

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

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 people 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 are willing to provide supported employment placements to people 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 group homes in the community or a more structured environment of an Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID).

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

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

#### Activities:

- Target pediatricians, early intervention, local health departments and health care practitioners 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.

## **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 insurances.
- 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.

## **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.

## **Objective #4: Strive to increase the quality and quantity of day programs to meet the needs of people with more severe/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/profound manifestations of ASD/DD behavior, such as the Neurobehavioral HOME Program and the Columbus Community Center.

## **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 needed.
- 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.

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

**Activities:**

- Work with health care practitioners/providers to develop screening for emotional and mental health stability in adults with ASD/DD.
- Develop leadership and support group opportunities for adults with ASD/DD, including outreach and awareness.

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

**Activities:**

- Support education to individuals with ASD/DD regarding self-advocacy, independent living skill, 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.

## 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 remote areas.

Access to screening, evaluation/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, ECHO, GATE, etc.)
- Facilitate dialogue among third-party payers, including Medicaid and 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, and treatment/therapy services.
- Encourage service organizations and other agencies to create and provide respite services and resources across the lifespan.

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

### Activities:

- Target pediatricians, early intervention 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.

## 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 autism awareness, acceptance, employment options, and interacting with individuals on the spectrum are 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.

**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 para-educators.
- Investigate endorsement and licensure requirements in other states.

**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.

- Develop and implement a system that connects individuals with ASD/DD to businesses and companies that fit their skillset.

**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 Vocational Rehabilitation (VR) counselors on how to interact with individuals with ASD/DD (The ACU and Sahara Cares developed a series of video training including Law Enforcement, Autism and Faith, and A Survival Guide for Caregivers).
- Develop and implement training for health care practitioners/providers to serve adults with ASD/DD.

**Objective #5: Teach and train practitioners/providers on the transition to adulthood for individuals with ASD/DD.**

**Activities:**

- Establish a method to train ASD/DD adult service system employees on the transition to adulthood.
- Develop and implement training for adolescent and adult health care practitioners/providers on the transition to adulthood for individuals with ASD/DD.

## 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, behavioral supports and understand and prepare for those changes.

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.

**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.

**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.

**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, post-secondary 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.

**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.

## Area 6: Research

### Background

The Utah Registry of Autism and Developmental Disabilities (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. 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/eligibility determination, services/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.

**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 that 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.

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