

*Proposed by Commission Chair*

*Vision - Goal*

*To make Autism an issue of diversity, not of disability – Marcus Autism Center*

All Individuals with ASD living the independent life, they choose.

Support systems in place, which create a life without limits.

Positive Effective Cross-Agency Coordination

- Partnerships
  - Universities
  - Private
  - Nonprofits
  - School Districts
  - State Agencies

Effective ASD Surveillance, Awareness and Outreach in Place

High-Quality Training of ASD Practitioners and Service Providers

Best Practice in Service Provision

- Recognize and Support Limitations in adaptive behaviors

Innovative ASD Services and Supports available across the Lifetime

Individuals with ASD have access to evidence based treatment regardless of age, functioning level, location, income, or insurance.

- Treatments which address the needs of the entire spectrum
- Delivery of research levels of treatment is standard practice
- Funding priorities, rates and mechanisms flexible enough to ensure access
  - a. Access to sufficient billing codes and sufficient reimbursement from 3<sup>rd</sup> party payers
  - b. Sufficient group of providers who accept Medicaid

Individuals and their families will have access to resources and knowledge/skills to make informed choices.

Individuals with ASD who wander and their families receive the supports needed to ensure safety.

Individuals with ASD have an effective mode of communication.

Individuals with ASD and their families will understand, identify and support skills of self-determination

Family Well-being

- Parents/Caregivers Empowered through Education, mentoring, support and training
- Comprehensive Community Mental Health Services for the individual and their family
- Family-Centered Planning

- Medical Home
- Access to Respite
- Easy Family Navigation
  - Awareness of Services, Supports, Resources and Treatment

Elimination of all disparities to a timely diagnosis and access to evidence-based treatment

- Comprehensive Evaluation prior to the age of 3, within 5 years by the age of 1
  - Currently Clinicians usually consider 18 to 24 months to be the earliest time to make a diagnosis of ASD. Recent Studies are indicating signs as young 6 months old.
  - Early detection is an essential component in reducing the level of disability associated with ASD through early intervention.
  - Nevada Pediatricians following American Academy of Pediatrician's Guidelines
- Co-occurring conditions are recognized and treated

Successful Transitions

Employment Supports, which support choice and lead to full-time employment

Housing options, which support choice

Nevada's First Responders have received training to understand the characteristics of ASD

Standardized Outcome Measures

- In order to truly determine the effectiveness of interventions and the outlook across the lifespan, measurements of outcomes that are responsive to intervention and quality of life measures that can help determine the effectiveness and impact of services must be identified and standardized.
- Statewide agency sharing and participation of data collection
- Longitudinal data on life course pathways and outcomes
- Person-Center outcomes strategies and measures

What outcomes are meaningful?

- Quality of Life
- Self-Direction

Updated Best Practice Guidelines to include Services Navigation Guidelines

It can be reality...

Nevadans with ASD are High School Graduates

Nevadans with ASD are College Graduates

Nevadans with ASD are employed

Nevadans with ASD have friends, enjoy hobbies, and leisure activities of their choice

Nevadans with ASD live where they choose

## Timeline

### Steering Committee

- Sub-committee chairs and Commission members

### Options to consider

Review current resources, supports, services, data, and gaps.

Develop statewide survey, conduct and analyze

Conduct Focus groups and analyze results (Workshop/Summit Format)

### July – The Start of Information gathering

Work assignments – for chairs, can utilize voting and non-voting members

May utilize support staff to collect via email or may hold in-person meetings

Individual brain storming

Questions for survey or Focus group in your content area

Could revamp surveys from other states

Collect from agency staff - information on current available resources, services and supports

Review presented documents, NV Autism Task Force Recommendations, Other State Plans

### August

Steering Committee Forum (members meet with MSA)

Goals

July information gathering sharing

### August/September

Subcommittees meet with MSA to run Workshop/Focus Groups

Agencies present on state of current services and supports for content area

Expert in content area presentation (by phone or in person)

Round Tables to address scope of work areas

Survey distribution

### October

Sub-Committees meet

Steering Committee Forum with MSA

Survey Collection Completed

Sub-Committee Reports drafted

### November

Send team to Ohio Center for Autism and Low Incidence (OCALI)

National Autism Leadership Summit, Tuesday November 18

Sub-Committee Reports Finalized

Steering Committee Forum with MSA

### December

MSA develops document, shared with Steering committee, presented to Commission, shared with public

Ohio Center for Autism and Low Incidence (OCALI)

National Autism Leadership Summit, Tuesday November 18

University Summit, November 21

The summits provide national leaders an opportunity gather and share information and best practices for:

- Informing and guiding public policy
- Strengthening and augmenting support systems
- Leveraging resources and materials

With the ultimate goal of improving outcomes to individuals with autism and disabilities across their lifespan.

Can TelMed Improve Access for Rural Areas?

Studies

- “Behavioral Treatment through in-home telehealth for young children with Autism.” Is evaluating the effectiveness of using in-home telehealth to deliver an empirically validated behavioral treatment for challenging behavior to families in underserved areas of rural Iowa.
- “Efficacy of the Home TEACCHing Program for Toddlers with Autism.” Is evaluating an innovative home-based version of the TEACH (Treatment and Education of Autistic and Communication-handicapped Children) program, which has been adapted to be more developmentally appropriate for toddlers with ASD and more responsive to needs of families in rural communities.
- Project aimed to improve access to evidence-based treatment for families of youth with ASD who live far from specialty medical centers. This study tested the feasibility and potential efficacy of using videoconferencing program to connect families of psychiatrically complex youth with ASD, living in rural Colorado, with clinical psychologists who specialize in treatment of anxiety and coping problems in youth with ASD. Telehealth delivery of the interventionist was found to be acceptable and feasible with promising preliminary efficacy for youth self-report of fears and anxieties and parent report of impact on family.