

# Nevada Department of Health and Human Services

February 20, 2007

Nevada Autism Summit  
Report – February 2006

## Introduction

The Nevada Autism Summit (**NAS**) was a 14-month project of the Nevada University Center for Excellence in Disabilities (Nevada UCED), funded by a grant through the Nevada Governor's Council on Developmental Disabilities. The primary objectives of the grant were: 1) to collect and organize comprehensive statewide data on lifespan issues related to Autism Spectrum Disorders (referred to hereon as PDD/ASD), from both a family and service provider perspective; and 2) to use the data collected to develop a position statement and preliminary action plan to address current and projected future needs statewide. Core staff for the **NAS** project were Candace Ganz (Assistant Director, Nevada UCED, UNR) and Debra Vigil (Associate Professor, Speech Pathology & Audiology, UNR). Dr. Ganz functioned as Project Director and Dr. Vigil functioned as Chair of the Steering Committee/Project Consultant-North. **NAS** staff also included Gwen Shonkwiler, who completed project evaluation activities. Matt Tincani (Assistant Professor, Special Education, UNLV) represented UNLV and served as Project Consultant-South on the Steering committee.

The first phase of the project involved identifying, creating, and engaging the collaboration of a steering committee that represented parents, advocates, service providers, educators, and agency representatives from urban and rural communities with expertise in PDD/ASD across the lifespan. The focus was then directed toward collecting comprehensive statewide data, and efforts culminated with a statewide summit for approximately 100 participants on November 11-12, 2005. During the summit, the data that had been collected to that point were disseminated and used to determine priorities for the development of a position

statement and preliminary action plan to address the identified needs and interests of the Nevada autism community.

### **Initial Activities**

**Background and Project Start-Up.** In June 2004, the Nevada Governor's Council on Developmental Disabilities announced the availability of funds to support projects during the 2004-2005 budget year. The request for proposals (RFP) identified "priority areas of interest for 2004-2005 funding" that included a "statewide autism summit ...to bring consumers, parents, and providers together to discuss ways to improve services for families with children of all ages with autism." In November 2004, the Nevada UCED was officially notified that their proposal had been selected for funding. The award was formalized and funds were dispersed in mid-January 2005.

**Project Goals.** Three primary goals were established for the **NAS** project. These goals were included in the proposal for funding, and guided the activities throughout the project. The goals were developed with a view to addressing the relevant history, assessing the current status, and laying the foundation for effective future planning for issues related to individuals with autism across the lifespan, and their families. The three specific goals were to:

1. Collect and analyze data from stakeholders statewide on lifespan issues related to PDD/ASD;
2. Use data collected through comprehensive surveys, the November summit, and follow-up activities, to develop a position statement and recommended action plan to address current and future needs; and
3. Begin to pursue private, state, and federal funding to support projects emerging from **NAS** recommendations.

**NAS Steering Committee.** In January 2005, **NAS** appointed a steering committee to provide guidance throughout the project. The group represented the state geographically, included parents of individuals with PDD/ASD, service

providers, and agency representatives, and represented a diversity of lifespan interests and experiences. From the 60 individuals recommended to project staff, 35 completed applications to participate. Core staff invited 17 to serve on the **NAS** steering committee, and all accepted.

**NAS Surveys.** The **NAS** survey instruments were designed to collect comprehensive information on experiences, needs, interests, and opinions related to PDD/ASD from parents and service providers/agency representatives. Four instruments were developed in English and Spanish and could be accessed at no cost by participants throughout Nevada online, in paper form, or by telephone:

1. Parent/Family Survey I: Background, Evaluation, and Diagnosis
2. Parent/Family Survey II: Intervention & Perceived Future Needs
3. Service Provider/Agency Representative I: Background, Evaluation, and Diagnosis
4. Service Provider/Agency Representative II: Intervention & Perceived Future Needs

As of February 2006, 524 surveys were completed: 237 by parents; and, 287 by service providers/agency representatives. Based on the quantitative and qualitative data collected to date, the following preliminary conclusions can be made:

1. Parents of children with PDD/ASD typically become concerned about their child's development between the ages of 1 and 2 years; diagnosis is, on the average, 3-4 or more years later. This delay in diagnosis is unacceptable for parents; it is more acceptable to and explainable by service providers.
2. Parents often feel that the professionals they first consult dismiss their initial concerns. They attribute this to being undervalued by professionals and to the lack of experience in the area of PDD/ASD by the average front line service provider.
3. Parents and service providers agree that services in Nevada are average at best, and below average in most instances. Parents' overall ratings of Nevada's services are significantly lower than the ratings of service providers.
4. Parents and service providers agree that Nevada is in critical need of

- qualified service providers. In addition to mandating an entry level of competence, vital issues involve provision of ongoing continuing education, and strategies to ensure successful recruitment and retention of qualified personnel.
5. Parents and service providers agree that Nevada is in critical need of improved, evidence-based services and related resources across the lifespan. Parents stress that these services and resources must be consumer/family driven and provide choices for consumers.
  6. Parents and service providers agree that an area of relative strength is the use of a multidisciplinary team in the service delivery process. There is less agreement regarding the role the family currently plays and should play on the team.
  7. Parents report that among the critical needs, the most urgent to address include: best practice services in early identification/diagnosis; access to choices in services and case management beginning with early intervention; improved/increased access to social skills training and sexuality instruction; and improvement in services for transition and adult interventions (e.g., job training, post secondary education, independent living)

**Nevada Autism Summit.** The Nevada Autism Summit was held on November 11 and 12, 2005, on the University of Nevada, Reno campus. Of the 103 confirmed participants, 70 attended the 1-1/2 day event. The agenda included brief presentations by **NAS** core staff, the DD Council Executive Director, Richard Weathermon, and Dr. Jennifer McFarland from the West Virginia Autism Training and Research Center. The remainder of time was spent engaging participants in facilitated breakout group discussions, and presenting, discussing, and prioritizing the results of the breakout groups. Outcomes of the summit were the development of prioritized Principles/values (**PV**) and recommended actions (**RA**) that covered comprehensive lifespan issues. Appendix C: *Nevada Autism Summit Participant Data: Values & Principles and Recommended Actions* is attached.

Core components of these outcomes include:

1. **PV:** All Nevadans with autism, and their families, should have access to choices in high quality, coordinated services throughout the lifespan that are consumer/family driven, evidence-based, and grounded in a respect for the individuals served and their diverse histories, needs, strengths, and interests.
2. **RA:** Nevada is in critical need of a state funded Center or Centers that

provide information, coordinate efforts, and function to effectively organize the provision of services for individuals with autism, their families, service providers, and related agencies statewide.

**Concluding Comments.** The **NAS** project met the three goals established. Core staff will continue to collect and analyze survey data and incorporate new information into future fund development and dissemination activities. The data will be available to support efforts to establish a statewide plan to effectively meet current and future needs. Results of the **NAS** project documented the wide array of unmet needs and challenges of a culturally, geographically, economically, and philosophically diverse state. Project efforts revealed many areas of accord as well as barriers to effective collaboration that exist across Nevada. The conclusion of core staff was that the most favorable foundation for future efforts would be through the establishment of a state funded Autism Network, developed around two interdependent centers (one north, one south, each with rural satellites), committed to a common set of framing values, and with a system of oversight and a mandate to collaborate.

**Update to this report:** The Nevada Governor's Council on Developmental Disabilities funded Phase 2 of the Autism Summit on July 1, 2006. Phase 2 will use data collected as part of the NAS and additional information gathered from other states to develop a comprehensive action plan to achieve the prioritized goals and objectives stated in the NAS final report.