

Nevada Autism Summit: Phase 2 Final Report

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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 project began January 1, 2005 and ended February 28, 2006. Activities, including a series of surveys for families and service providers, and the 1-1/2 day summit, resulted in a series of prioritized principles/values and recommended actions that covered service delivery, professional preparation, policy, and information dissemination. The final report was presented to the DD Council during their February 2006 meeting, and to the Governor's Strategic Planning Accountability Committee (SPAC) in April and May 2006. The current project, Nevada Autism Summit: Phase 2 (**NAS:2**) was a 6-month project of the NV UCED, and an outgrowth of the original **NAS** activities. Again funded by the Nevada DD Council, it began July 1 2006, and ended December 31, 2006. The goals of **NAS:2** were to:

1. Clearly define a vision for Nevada, with regard to meeting the needs of individuals with ASD/PDD across the lifespan;
2. Propose an action plan for reaching that vision that includes:
 - Goals
 - Objectives
 - Activities
 - Timeline
 - Responsible parties/Collaborating partners
3. Outline projected costs and potential sources of funding; and
4. Propose a monitoring plan to support the implementation process

HISTORY AND BACKGROUND

In their call for proposals in the summer of 2004, the Nevada Governor's DD Council specifically requested submissions for a statewide autism summit. The original Nevada Autism Summit project was funded to address the goals of creating statewide collaborations, collecting statewide comprehensive information, and developing a position statement and set of recommended actions for the state of Nevada. Outcomes included completion of comprehensive survey information from more than 500 parents and service providers, which together with the products from the 1-1/2 day summit led to the development of the following position statement and preliminary action statement.

Position Statement

All Nevadans with autism, and their families,
 should have access to **choices** in **high quality, coordinated** services throughout the **lifespan**
 that are **consumer driven, evidence-based**, and grounded in a **respect** for the individuals and their
diverse histories, needs, strengths, and interests.

Preliminary Action Statement

Consumers in Nevada are in critical need of:

- Competent professionals to provide services across the lifespan
- Consumer driven choices in quality services across the lifespan
 - Access to comprehensive and valid information

CURRENT PROJECT

As reported earlier, the charge of this project was to build on the outcomes of the original project in order to: define a vision for meeting the needs of individuals with ASD/PDD across the lifespan; and, propose an action plan for reaching that vision. In order to accomplish those goals collaboratively and efficiently, a timeline was established. The activities and outcomes associated with this timeline are as follows:

Month	Activity	Outcome
1	1. Convene steering committee; share plans; collect and organize committee input; assign related tasks, if appropriate.	Met
	2. Organize background information from state and federal sources.	Met
	3. Collect information on state plans and activities from states with well-regarded autism programs.	
	4. Collect published information on best practice services for individuals with autism throughout the lifespan.	Met
	5. Organize current information on services for individuals in NV with autism.	Met
2	6. Continue with previous activities, as appropriate	Met
	7. Visit 2-3 state programs for in-depth discussion with program leaders	Postponed
3	8. Continue with previous activities, as appropriate	Met
	9. Visit 1-2 state programs for in-depth discussion with program leaders.	Postponed
	10. Convene steering committee; share progress; collect and organize committee input; assign related tasks, if appropriate.	Met
4	11. Continue with previous activities, as appropriate	Met
	12. Schedule and conduct 2-3 focus groups in northern, southern, and rural Nevada to discuss issues related to a state implementation plan.	Deleted
5	13. Continue with previous activities, as appropriate	Met

	14. Schedule and conduct 2-3 additional focus groups in northern, southern, and rural Nevada to discuss issues related to a state implementation plan.	Deleted
	15. Added: Meet with state representatives at 2 national/international meetings in Washington D.C. and Miami, FL.	Met
6 (&7)	16. Continue with previous activities, as appropriate	Met
	17. Schedule and conduct 2-3 additional focus groups in Northern, southern, and rural Nevada to discuss issues related to a state implementation plan.	Deleted
	18. Generate and submit final report, including: <ul style="list-style-type: none"> ▪ Summary of current status ▪ Prioritized plan, including goals and objectives ▪ Timeline for reaching goals and objectives ▪ Associated costs & potential funding sources ▪ Monitoring Plan 	Met
	19. Convene steering committee; review final report draft.	Met

The majority of projected activities occurred as planned; however, some modifications occurred. An explanation of activities and revisions to original plans follows.

Steering Committee activities. All original steering committee members were asked to continue serving during Phase 2. Of the 13 active members from Phase 1, nine indicated that they wished to continue. One new parent member, who participated in the Phase 1 summit, was added to replace a parent who was no longer able to continue. Of the ten committee members who agreed to serve, eight participated actively in the three meetings held; the other two attended and/or participated minimally.

The steering committee met three times, approximately once every other month. Meetings were held by videoconference, with sites in both Reno and Las Vegas. Activities included discussing Phase 1 recommendations, discussing activities and projects from other states, prioritizing recommendations for Nevada, discussing potential funding sources and collaborating partners for Nevada projects, sharing information about developing state and local programs, and other related topics. At the final meeting, the outline for the NAS: 2 final report was reviewed and discussed; steering committee members provided input regarding the proposed content, including recommendations and priorities.

Background information from state and federal sources. Information was collected from other states in a number of ways. During Phase 1, data on state websites, programs, projects, and other related activities were compiled from websites and personal contacts. During Phase 2, additional information was compiled from state and national websites, published reports, and

personal contacts with representatives from state and federal programs. Some of the critical data are outlined below.

Facts and statistics from the Autism Society of America (www.autism-society.org) indicate the following:

- 1 in 166 people are born with ASD (Latest figure from Center for Disease Control: 1 in 150)
- 1 to 1.5 million Americans have an ASD
- ASD is the fastest-growing developmental disability
- ASD has a 10-17 percent annual growth rate
- Growth comparison of ASD during the 1990s
 - U.S. population increase: 13 percent
 - Disabilities increase: 16 percent
 - Autism increase: 172 percent
 - \$90 billion annual cost
- 90 percent of costs are for adult services
- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention
- In 10 years, the annual cost will be \$200-400 billion

The Autism Society of America obtained their data from Center for Disease Control, U.S. Department of Education. Economic impact data were based on a report by K. Jarbrink and M. Knapp from the London School of Economics study (2001).

For Nevada, extrapolating the prevalence of 1 in 166, based on live births (35,188) from the U.S. Census Bureau in 2004, suggests that 212 children born in 2004 have now been diagnosed with autism. These data indicate that approximately every other day a child born in Nevada will be diagnosed with autism. If the latest figure of 1 in 150 is taken to calculate the number of children born with an autism spectrum disorder, this puts the figure of the number of children born in 2004 even higher – to 235. This does not account for immigration from other states, nor does it account for the consistent population increase in which Nevada has been ranked as the fastest growing state for the past 19 years (U.S. Census Bureau, 2007).

Currently the Center for Disease Control funds a total of 16 sites in 18 states to conduct surveillance of ASD and related developmental disabilities. The states are funded through two different systems, the Autism and Developmental Disabilities Monitoring (ADDM) Network and the Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (CADDRE). Together they are titled the ADDM CADDRE Surveillance Network. Through the ADDM Network the following states are funded: Alabama, Arizona, Arkansas, Florida,

Georgia/CDC, Missouri/Illinois, New Jersey, South Carolina, Utah, and Wisconsin. The goals of ADDM include: "(1) develop or improve programs to track the number of children with an ASD in their states; and (2) provide comparable, population-based estimates of the prevalence rates of autism and related disorders in different sites over time." (CDC, 2007). The investigators in the ADDM system typically collaborate with universities within individual states and agencies within state governments such as Departments of Maternal and Child Health, Departments of Education, Departments of Health, etc. Each ADDM site reports various types of programs they provide, including continuing education courses for professionals, diagnostic evaluations, enhancing capacity for early identification, education, community outreach, support for families, developing educational programs for professionals, and/or service coordination throughout the state.

The following states are funded through the CADDRE Network: California (California Department of Health Services, Colorado (Colorado Department of Public Health and Environment), Georgia/CDC, Maryland (Johns Hopkins University), North Carolina, and Pennsylvania (University of Pennsylvania/The Children's Hospital of Philadelphia). The goals of CADDRE include: (1) improve community and service provider awareness; and (2) conduct epidemiologic research. This network researches biomedical causes for ASD and issues closely aligned with the ADDM Network, including perinatal factors, environmental factors, gastrointestinal problems, genetics, screening practices, evaluation of cost and utilization of services, and supports for parents who manage issues such as medical/therapeutic/educational services.

The population age range for the ADDM CADDRE Surveillance Network varies from site to site. Some studies focus on 18-24 months, some 3-5 years, 3-11 years old, 3-8 years old, and others 3-21 years of age. The geographical scope varies as well. Some states focus on one county or one city while others attempt to obtain information from multiple counties (range: 1 – 23 counties). For more information, see www.cdc.gov/ncbddd/dd/aic/states/index.htm.

Focus Groups. After discussion with steering committee members, project staff decided to cancel plans to hold focus group meetings. This decision was based on the projected costs involved, the short timeline, and the availability of alternate ways to obtain input. Instead of the focus groups, the **NAS** surveys, which were disseminated during Phase 1, were kept open as a vehicle for allowing consumers throughout Nevada to share their input. Throughout Phase 2,

efforts were made to reach potential respondents who had not already completed the surveys. By the end of Phase 2, more than 700 surveys had been completed.

Review /consolidate NAS recommendations. Following the summit in November 2005, the recommendations generated by the summit participants were combined with recommendations from consumers who had completed surveys. As a result, 32 formal recommendations were proposed, which spanned issues across the lifespan, across cultures, and throughout the state. These recommendations were then grouped, according to focus. After this analysis was completed, all recommendations were found to focus on one or more of the following three needs:

- Information Dissemination
- Training – both professional and family
- Service Delivery

Using these three central needs as a starting point, three formal action statements were developed, each of which include two or more recommendations. These action statements and recommendations are listed below, along with rationales and the needs addressed in each area.

I. Support access to current and valid information for consumers, parents/families, service providers, agencies, and other interested persons

Needs addressed: Information dissemination (initially); potential for training and research

Rationale: Lack of access to current and valid information was a pervasive theme that ran through all topics. The types of data needed by consumers, including self-advocates, families, service providers, and agency representatives included general information about autism, current research, services available in Nevada and elsewhere, legislative business, training information, related activities occurring throughout Nevada and neighboring states, etc.

Recommendations:

1. Develop and maintain a comprehensive website for the state. The initial focus of this website should be on dissemination of existing information and provision of links to other valid and reputable websites.
2. Once developed, the website project should expand to provide online training, support related research, and incorporate features that would support interactive components.

II. Support education/professional preparation

Needs Addressed: Information dissemination and training

Rationale: Eighteen of the 32 recommendations made at the **NAS** speak to the need to provide a wide range of autism related information and educational opportunities for Nevada's teachers, service providers, and family members.

Recommendations:

1. Develop an annual special forum series on autism for both parents/families and professionals. Include options for university credit, continuing education credits, clock hours, and certificates of completion.
2. Support development of a wide range of educational opportunities for self-advocates, parents/families, and professionals in various formats and throughout the year; support and promote awareness of these opportunities to potential participants throughout the state.

III. Support access to choices in evidence based services throughout the lifespan.

Needs Addressed: Service delivery

Rationale: Nine of the 32 recommendations made at the **NAS** deal with matters related to accessibility of services, funding for services, and related policy issues.

Recommendations:

1. Support legislative action that will result in Autism being determined a medical diagnosis, across the lifespan.
2. Support legislative action that will result in services for individuals with Autism diagnosis, including evidence based interventions, being covered at the same rate as other developmental disabilities, through private insurance, Medicaid, and waiver programs.
3. Support legislative action that will result in speech generating devices being designated medically necessary equipment.
4. Support development of new programs and projects that focus on increased access to choices in evidence-based services for individuals across the lifespan.

Nevada Comparison Pool. **NAS:2** focused on collecting information from states in the Midwest/Western United States to make a valid comparison for services for individuals with autism. This decision was based on Nevada's geography, population density, urban-rural features, and proximity to the states surveyed. Seventeen states were surveyed and are listed in alphabetical order: Arizona, California, Colorado, Idaho, Kansas, Montana, Nebraska, Nevada, New Mexico, North Dakota, Oklahoma, Oregon, South Dakota, Texas, Utah, Washington, and Wyoming.

Information obtained from state websites. To gather data in a systematic way and to determine the level of involvement at a state government level, the Internet was initially used obtain information. Individual state government sites were accessed, e.g. State of Washington, State of Oklahoma; and the word 'autism' was put into their search engine. Personal contacts, either by phone or in person, followed the Internet research, to collect additional information and/or to clarify information. In all cases, the target states were studied with regard to the following questions:

1. Is there an official state website for autism?

2. What state departments are involved with providing services for individuals with autism?
3. Is there a task force?
4. Has there been or is there a Senate Bill?
5. Does the legislature provide funding?
6. Is there a collaboration between state government and universities?
7. Is there a physical center?
8. Does the state provide assessment to the public?
9. Does the state provide intervention to the public?
10. Does the state provide training for professionals and/or parents?
11. Is there an autism waiver in the state?
12. Is law enforcement provided with training?
13. Are there annual workshops for professionals and/or parents?
14. Does the state get additional funding?

Results. A summary of results is as follows. A table outlining these results can be found in Appendix 1.

1. State websites
 - 13 states do have websites
 - 4 states do not: Nevada, Montana, Texas, Wyoming.
2. State Programs
 - 4 states have programs through the Dept of Health
 - 3 have programs through the Dept of Education
 - 4 have programs that are a combination of Depts of Education & Health
 - 6 states do not have programs listed as having funding through state departments, which include: Idaho, Montana, Nevada, North Dakota, Texas; Wyoming.
3. Task Forces
 - 9 states do have Autism Task Forces
 - 7 do not: Idaho, Nevada, Montana, Wyoming, New Mexico, North Dakota, Texas
 - 1 - not sure
4. Senate Bills
 - 7 states do have senate bills
 - 7 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, Texas, Wyoming;
 - 3 not sure.
5. State legislative funding
 - 9 states do get funding from their state legislature, which ranges from \$125,000/annually (South Dakota) to \$17.2 million (California)
 - 7 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, Texas, Wyoming
 - 1 not sure
6. University associated
 - 11 states have programs that are associated with a university
 - 6 do not: Idaho, Nevada, Montana, North Dakota, Texas, Wyoming
7. Is there a state Autism Center
 - 8 states do have a Center
 - 7 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, South Dakota, Wyoming
 - 1 not sure

8. Do states provide Assessment services
 - 10 states do provide assessments
 - 7 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, South Dakota, Texas, Wyoming
9. Do states provide Intervention services
 - 9 states do provide some type of intervention services
 - 8 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, South Dakota, Texas, Wyoming
10. Do states provide Training
 - 12 states do provide training
 - 5 do not: Nevada, Montana, North Dakota, Texas, Wyoming
11. Do states provide Waivers
 - 4 states do provide waivers,
 - 11 do not: Arizona, Idaho, Kansas, Nevada, New Mexico, North Dakota, Oklahoma, South Dakota, Montana, Utah, Wyoming
 - 2 not sure
12. Do states provide law enforcement training
 - 6 states do provide some type of law enforcement training
 - 11 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, South Dakota, Nebraska, Texas, Wyoming.
13. Do states offer annual conference/workshops
 - 10 states do
 - 7 do not: Idaho, Nevada, Montana, New Mexico, North Dakota, Texas, Wyoming
14. Do states receive additional funds for their programs and services
 - 5 states get federal funding through the ADDM CADDRE Surveillance Network
 - 12 do not get direct federal funds.

Summary of state website data. Appendix 2 provides a narrative summary of services in each state surveyed. Generally, there were three states for which there was no information documenting the existence of any of the outlined programs, projects, collaborations, and/or services: Nevada; Montana; and Wyoming. Idaho, North Dakota, and Texas reported some programs and services, but they were limited. There were seven states with more comprehensive programs services, although they may not have a waiver, law enforcement training, or direct federal funding: California, Colorado, Kansas, Oklahoma, Utah, Oregon, and Washington. Overall, it was evident that while no state documented having all components, Nevada was clearly lacking when compared with many of the others.

Phone interviews. Once the state websites had been reviewed, an attempt was made to have phone contact with individuals from various programs. For some of the states that had extensive services, it was difficult to find an individual that could provide detailed information. Individuals from six states were able to provide information that could be useful for the present

project: Colorado, Idaho, Indiana Resource Center, New Mexico, South Dakota, and Utah. The following are questions asked of individuals; a summary of answers is outlined after each question.

1. What type of service did you begin with?
 - The majority of the programs began simultaneously with assessment and training.
2. How did you prioritize your activities?
 - Most services were developed as a result of parent involvement and state task forces to move their agendas forward. The primary focus was assessment and intervention services.
3. Did you begin with training service providers, parents, or both?
 - Initially, programs began with training of service providers. They then later added a parent-training component.
4. Where did you get your initial funding?
 - Initial funding ranged from state appropriations to state and federal grants. Subsequent funding included line items from the state, federal grants, fees for services, conferences, and workshops.
5. What personnel did you start with?
 - Consistent across the programs were psychologists, speech pathologists, and occupational therapists.
6. Did you initially have a central location for services? If so, what was that?
 - Most programs do not have center-based services, but do have a central base. For example, Colorado, New Mexico, and South Dakota provide direct services through government agencies and or university programs. These services include: (1) training to parents and professionals through inservices and workshops and (2) multidisciplinary team assessment clinics. The Indiana Resource Center for Autism is a web-based program that does not offer direct services, but provides training, a quarterly newsletter, educational outreach, research, individual consultation, and maintaining a website.
 - The state of Utah was unique in that it does have several centers. They started their program in the early 1980s at a mental behavioral unit, which included all children with disabilities. They then changed their focus to autism and began to duplicate their center in other locations. They now have three centers across the state.
7. Do you have a general coordinator for statewide services?
 - There did not appear to be one person who coordinated all of the services throughout the states. However, states maintained a website that is managed from a central location. For example, the Indiana Resources Center for Autism maintains an outstanding website for educational purposes for parents and professionals, maintains a calendar for various events related to autism, provides training, and holds conferences on various topics. Oklahoma works in the same manner. Colorado has a website that is maintained by the Department of Education. In Utah, they initially had one center, but realized that it was not practical for such a big geographical state. So they eventually developed independent centers.
8. What are your eligibility criteria?
 - This is based on the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) published by the American Psychological Association. For program evaluation, several individuals reported that the state of New York, Department of Education, published a

manual in 2001 entitled "Autism Program Quality Indicators: A self-review and quality improvement guide for schools and programs serving students with Autism Spectrum Disorder" (APQI). This can be accessed at

www.vesid.nysed.gov/specialed/autism/apqi.htm. An additional document referenced for program evaluation is an APQI from New Jersey. This can be accessed through Education Resources Information Center #ED486480. A .pdf file is available through Dr. Debra Vigil at the UNR Speech Pathology and Audiology Department.

9. Do you have state statutes mandating insurance coverage?
 - No one reported mandated insurance coverage.
10. Are there any services covered by a Medicaid Waiver?
 - Colorado had a program where they provide coverage for 75 children at a time, which includes assessment and a school program for one year.

Summary of phone interviews. Most states began their direct services with assessment and training. The training component began with professionals and developed into offering training for families. Prioritization of services was based on need, with feedback from parents. Eligibility criteria were based on the DSM IV manual published by American Psychological Association. Initial personnel involvement included psychologists, speech pathologists, and occupational therapists. There was neither a statewide coordinator nor a central location for the states, but a website was maintained to provide researched-based guidelines for parents and professionals. Initial funding varied from state appropriations to state, federal, and private grants. There was one state with a Medicaid waiver.

PRIORITIZED RECOMMENDATIONS

The conclusions and recommendations that resulted from the original **NAS** could be grouped into actions that involved three primary needs:

- Dissemination of valid information to consumers, families, and service providers (ID)
- Improved service delivery (SD)
- Improved training options for families and service providers. (Training)

Based on input from the steering committee, summit and survey participants, and representatives from agencies and programs across the country during **NAS: 2**, eight specific recommendations are made, in order of priority, to address Nevada's three primary needs.

These prioritized recommendations, along with projected timelines, collaborating partners, costs, and focus areas are presented in the following table.

Priority	Activity	Timeline	Collaborating Partners	Projected Costs	Focus Area(s)
1.	Website	3 months to develop and launch	UNR, DD Council, DHHS	\$9000 to develop; \$2500/year to maintain	1. ID 2. Training
2.	Support legislative action	Current legislative session	Consumers & advocates statewide	None	SD
3.	UNR Screening/Assessment Clinic	Pilot has begun; expansion possible with funding	UNR SPA Department and community partners	\$12,000/year to fund 1 full screening day each month	SD
4.	Community Screening for Early Identification	With funding, clinic could begin after 2 months of preliminary work	UNR, DHHS, BEIS, Early Head Start, Child Care Centers, other community partners	2-yr pilot - \$150,000	SD
5.	Annual Forum Series	Planning to begin 1 year prior to launch date	UNR, UNLV	\$40,000/year to fund a 5-part series	Training (professionals & parents)
6.	UNR Hanen parent programme	Present training is specific for language delay. Expansion possible with funding for autism.	UNR SPA Department	Initial start up for therapist training - \$8000. Training series for parents 2 times yearly - \$3000	1. Training (parents) 2. SD
7.	Rural Outreach	Planning to begin 1 year prior to launch date	Universities, BEIS, community service providers	\$50,000 to establish; goal to become self-sustaining	1. SD 2. Training (professionals & parents)
8.	Monitoring Plan	Ongoing	Steering committee	\$2000/year	1. ID 2. SD 3. Training

RELATED ACTIVITIES

Since the completion of the original Nevada Autism Summit in February 2006, several autism-related projects and activities have begun to take shape that promise to have both regional and statewide impacts. These include:

UNLV Autism Center. In October 2006, the NSHE Board of Regents approved the creation of the UNLV Center for Autism Spectrum Disorders. In a memo to the UNLV Campus Community on October 16, 2006, Vice Provost for Academic Affairs Michael W. Bowers reported the following:

Please note that the UNLV Center for Autism Spectrum Disorders (CASD) was approved at the October 2006 NSHE Board of Regents meeting.

The prevalence of individuals with autism spectrum disorders (ASD) has increased dramatically. There is a demand for high quality research and training to support the growing population of people with ASD in Southern Nevada and nationally. Currently, there is no university-based, multidisciplinary resource for people with ASD in the region. The UNLV Center for Autism Spectrum Disorders (UNLV CASD) will conduct research on characteristics, assessment, and effective intervention of persons with ASD and their families. Goals of the Center will also include ASD screening, assessment, education, and outreach to the Southern Nevada community, as well as procurement of external funds to support Center activities. The center is housed in the Department of Special Education in the College of Education. The date of initiation was November 1, 2006. This is under the direction of Dr. Matt Tincani and can be contacted at Phone: (702)895-2965 E-Mail: tincanim@unlv.nevada.edu

Camelot Schools. In November 2006, the NAS: 2 Project Director was contacted by Rella Peeler, the Superintendent of the Camelot Schools (www.thecamelotschools.com). The Camelot Schools, a 30-year old Company, includes a network of residential treatment centers, therapeutic day schools, and alternative education programs in Illinois, Pennsylvania, and Tennessee. They focus on serving children with ASD, severe emotional disorders, and severe multiple disabilities – and their families. At the time of the contact, they were exploring the possibility of expanding their network of centers, and had determined that Nevada was a potential future site. According to Ms. Peeler, they were gathering information on Nevada's needs, policies, and practices and would evaluate their future action plan at that time. In addition to this office, Ms Peeler was also contacting representatives from the Department of Education, Clark and Washoe County School Districts, and others.

UNR Screening/Assessment Clinic. Under the direction of Dr. Debra Vigil, an assessment clinic at the UNR Speech and Hearing Clinic is being developed to evaluate children for possible

autism. As recommended by the National Institute of Health, the assessment is conducted by a multidisciplinary team, which includes the following professionals: child psychiatry; developmental education; occupational therapy; psychology; social work; and, speech-language pathology. To date, the group has met four times on a voluntary basis and plans on meeting on a monthly basis. To meet on a more consistent basis and to duplicate this team, further funding is required. Discussions have been conducted with the Dean and the Chief Financial Officer of the School of Medicine at UNR seeking funding.

Hanen Parent Training Programme – expansion. Presently, through the Department of Speech Pathology and Audiology, a yearly parent training class called the Hanen Programme is offered to parents of children with a language delay to help parents facilitate their children's language ability. The Hanen Programme offers certification of their program to Speech-Language Pathologists (SLP) to conduct the program. Hanen offers specialized training specifically for parents of children with autism. This program can be expanded to offer training to parents of children with autism.

Community Screening for Early Identification Pilot Project. The Center for Disease Control recommends population screening for early identification of children with autism to get them into the early education system for intervention services. A pilot project is in the planning stages that will target child care centers, doctor's offices, and Nevada Early Intervention Services for identification and will include training of nurses, child care workers, and developmental specialists to provide research-based information regarding identification of signs of autism and make appropriate referrals. Discussions have been conducted with the Director of Health and Human Services, the Director of Mental Health and Developmental Services, Director of the Health Division, Chief of Early Intervention Services, and Chief of Community Health to explore possible funding.

UNR graduate concentration. Through the Department of Educational Specialties at the University of Nevada Reno, graduate students in special education have the option to pursue a concentration in autism, leading to the autism teaching endorsement in Nevada. Contact: Shannon Taylor, Ph.D.

UNLV graduate emphasis. Through the Department of Special Education at the University of Nevada Las Vegas, students pursuing a graduate degree in special education have the option to

complete an emphasis in autism that will lead to the autism teaching endorsement in Nevada.
Contact: Matt Tincani, Ph.D.

PBS expansion. The Positive Behavior Support program, a project of the Sierra Regional Center and the NV UCED, expanded during the past year, creating a project to better serve consumers in the Las Vegas area. This new project serves many individuals with autism, their families, and their service providers. Contact: Matt Tincani, Ph.D.

SUMMARY

The **NAS: 2** project collected and organized comprehensive data from the original Nevada Autism Summit, from the **NAS** survey project, and from other state programs and projects in order to set specific goals to support improvement in Nevada. As a result, three action statements were developed, which included eight specific recommendations. Eight activities were then developed from the recommendations in order to lay the foundation for significant improvements in information dissemination, training, and service delivery for consumers, families, and service providers throughout Nevada. Implementation of these activities would significantly improve autism supports throughout the lifespan, as well as optimize the efficient functioning of current programs and projects.

Nevada's current needs for services, information, and training in autism are critical. These needs will only continue to escalate as the numbers of newly diagnosed children impact the state's prevalence and those individuals already diagnosed mature. It is essential to begin to meet the current needs now, and to begin to plan for a future that will support individuals and families throughout Nevada.

APPENDIX ONE

**Table of Summary of Services Offered for
Individuals with Autism in Western United States**

	Official Website	State Agency	Task Force	Senate Bill	Legislative Funds	University Association	Center	Assessment	Intervention	Family/Professional Training	Waiver Program	Law Enforcement Training	Workshop/Conference	Additional Funds
AZ	√	√	?	?	√	?	?	√	√	√	x	x	√	√
CA	√	√	√	√	√	√	√	√	√	√	√	√	√	√
CO	√	√	√	√	√	√	√	√	√	√	√	√	√	√
ID	√	x	x	x	x	x	x	x	x	√	x	x	x	x
KS	√	√	√	√	√	√	√	√	√	√	x	x	√	x
MT	x	x	x	x	x	x	x	x	x	x	x	x	x	x
NE	√	√	√	?	?	√	√	√	√	√	?	x	√	x
NV	x	x	x	x	x	x	x	x	x	x	x	x	x	x
NM	√	√	x	x	x	√	x	x	x	√	x	x	x	x
ND	√	x	x	x	x	x	x	x	x	x	x	x	x	x
OK	√	√	√	√	√	√	√	√	√	√	√	√	√	x
OR	√	√	√	√	√	√	√	√	√	√	√	?	√	√
SD	√	√	√	?	√	√	x	√	x	√	x	x	√	x
TX	x	x	√	x	x	x	√	x	x	x	x	x	x	x
UT	√	√	x	√	√	√	√	√	√	√	x	√	√	√
WA	√	√	√	√	√	√	√	√	√	√	√	√	√	x
Total Yes	13	11	9	7	9	11	8	10	9	12	4	6	10	5
Total No	4	6	7	7	7	6	7	7	8	5	11	11	7	12
Total Unsure	0	0	1	3	1	0	2	0	0	0	1	0	0	0

APPENDIX TWO

Narrative Summary of Services for each Comparative State

Arizona: Nice information immediately. However, there is no direct information about how & where to get services. They are part of the ADDM Network funded by CDC, but they do not provide direct services. There is the Tucson Alliance for Autism which has 4 organizations: University of Arizona Speech, Language, and Hearing Sciences, Autism Society of America Chapter, Pima County Chapter, Mid-America Association for Autistic Training and Research, Tucson Autism Community Center. Pamela Crooke at U of A is the SLP on the Interdisciplinary Diagnostic Team.

California: Excellent website: enter autism & gets you to department of Developmental Services. Publications are available on a range of topics, e.g., for best practices in assessment. Many programs are offered through universities to get services & through regional centers. In looking at one regional center – Alta Regional Center, serving northern California (Sacramento) – It has its own website - Offers parent training in ABA – Links to Autism Society & different departments in California.

Colorado: Through the Dept of Education, they have extensive information & brochures on autism. They are holding a conference in Sept 2006 related to training of service providers and parents. Contact to ask re services: Gina Quintana: 303-866-6605.

They are part of the CDC Task Force: Colorado Dept of Public Health, JFK Partners at Senate Bill 177 passed and \$2 million in funding was provided, autism waiver, Colorado Manual on working with Children with Autism Spectrum Disorder

Colorado Autism Task Force goals:

- Establish greater public awareness of autism
- Establish foundation for a network of statewide resources re autism
- Provide information about services to parents & service providers
- Identify guidelines for measurable educational & instructional goals that can be used by members of the education community for serving children with autism
- Establish a set of guiding principles for serving children with autism
- Establish a set of guiding principles for the training of educational service providers and parents

Idaho: Nice information that provides basic facts about autism, then resources outside of the state Institute of Rural Health: Barbara Cunningham: cunnbarb@isu.edu 208-282-4436. There doesn't appear to be any services provided.

Kansas: They have a Governor's Commission of Autism that consists of 15 members appointed by the Governor. Their Senate education committee estimates that serve children 0-5, the cost would be 1.2 mil for 100 children; \$2535/mo per child; \$30,426/yr per child. That includes case management to coordinate necessary services & assist family, respite care, expanded speech & physical training, & social skills training. Not an easy site to navigate. They have on line training at the Child Development Center at University of Kansas. They are part of the Southwest Autism Research & Resource Center. Dr. Matt Reese at University of Kansas Medical Center has an Autism/Asperger Resource page. They have an Early Childhood Autism Program, which is not in service at this time.

Their website provided information on Professional Development in Autism (PDA). There are centers in Washington, Colorado, Kansas, Ohio, Maryland, and Florida. They have a goal to provide training and consultation to school teams for diagnostic and intervention purposes. It is funded by US Dept of Education – Office of Special Education Programs. There are links to Project Data in Washington. The PDA Center is located at the University of Washington Experimental Education Unit. This is part of the Data Project.

Montana: Nothing

Nebraska: They have what is called the Nebraska ASD Network which was requested by educators and parents through the Special Populations Office of the Nebraska Dept of Education. They have a Project Coordinator for Autism Spectrum Disorder. They have a nice booklet that discusses the Nebraska State Plan. Laura Maddox is the state coordinator: 402-450-6298; lmaddox2@unl.edu. They are providing training on visual strategies, sensory integration, assistive technology, assessment. www.nde.state.ne.us/autism. They have a brochure called Next Steps – A guide for families new to ASD, funded by the State Dept of Education, Autism society of Nebraska, & Wal-Mart. This provides general information about autism and resources. They did have a series of workshops.

Nevada: There are references to Candace Ganz' presentation to SPAC

New Mexico: The Public Education Dept have a nice handbook of technical services for guidance on providing support & services, pg 38 gives a chart on prevalence & cost associated with it, which was published June 2004. They obtained a grant from the U.S. Department of

Education to write the manual. Project SET is from the Center for Development & Disability: Primary Authors: Pat Osbourn, Fletcher Scott. The Family Infant Toddler (FIT) Program is another organization for services.

North Dakota: They have guidelines, but there doesn't appear to be many services.

Oklahoma: Through the Dept of Special Ed, they have specialized training called Special Education Autism Registry Trainings. There is a website by the Oklahoma Autism Network. They are developing & expanding resources through collaboration with state agencies and other organizations. They had an Autism Working Group that met for 2 years in which the group collected information. They heard from parents & professionals and developed an Oklahoma Plan. They have a Child Safety ID Card that can be filled out and downloaded that has information about Diagnosis, medical requirements, communication method, & behavioral patterns. The website has basic info, etc. They have a webcast from the CDC entitled Autism Among Us: Rising Concerns and the Public Health Response, www.publichealthgrandrounds.unc.edu/autism/webcast.htm.

They have Pilot Program to provide in home support to 30 children with autism & their families. They are doing trainings through the University of Oklahoma Health Sciences Center/Center for Learning & Leadership/UCEDD, Child Study Center, Project PEAK. Professional Development in Autism (PDA). Contact: Dianne Mathis – Dianne-mathis@ouhsc.edu; 405-271-6824 x45143, Oklahoma Autism Network, Oklahoma Developmental Disabilities Council. 6-day training. . The Oklahoma Autism Network was developed to 'provide evidence-based information about autism and information about resources available in the state for Oklahomans with autism, their families, and the professionals who support them.' This was funded by Developmental Disabilities Service Division, Dept of Human Services.

Oregon: There is a program through Portland State University: ASD Outcome Study & Training Project (1998) - www.autismstudy.pdx.edu – They are collecting statewide data to have a database of student characteristics, assessment data, program implementation strategies for longitudinal tracking. Through the Department of Education, they are setting up Regional Program Autism Training Sites (RPATS) to train special educators to effectively teach children with autism. Training centers are beginning with: early childhood, primary elementary, upper elementary, middle school, then high school. There will be regional autism specialists that will provide training. Jay Gense (O.D.E.) jay.gense@state.or.us. In addition, the Child Development and Rehabilitation Center (CDRC) at Oregon Health & Science University (OHSU) has joined

forces with other university-based medical centers to form the Autism Treatment Network, which is committed to improving treatment options for individuals with autism and their families. Finally, there was a Senate Bill 765e passed July 1999 that appointed task force. They met for 6 days and had many recommendations. One outcome was that the Oregon legislature approved providing funding specifically for autism.

South Dakota: Through the University of South Dakota, School of Medicine & Health Sciences they have an autism spectrum disorders program to provide information, training, evaluation services, consultations and family support groups. www.usd.edu/cd/autism. It was established in 1989 through the efforts of parents. They have Administrative rules developed by the legislature regarding screening, definition of autism, diagnostic procedures, instruments to be used. The evaluation clinic is held on Mondays & Tuesdays at Augustana College, Sioux Falls & Health Science Center in Sioux Falls. They provide trainings that include: Visual strategies, Floortime/DIR, Teaching language skills to children, fluency based instruction. They work with the Autism Society of the Black Hills and they have an Autism/Asperger's Family Summer Camp. Contact is sheritony@rap.midco.net or www.autismsd.com. One person who is providing classes is Lynne Rick, Education Specialist with the Center: Irick@usd.edu. As part of their website they have a 'topic' page where there is great information that can be useful for parents and providers alike. They have a handbook that provides nice info including a nice write up of intervention techniques.

Texas: Texas has one privately funded autism center in Dallas with another opening in San Antonio in the near future. These are called the Autism Treatment Centers. The governor of Texas recently convened a Task Force and their report was released in December 2006 in which they outline the services needed for the state.

Utah: Through the Dept of Community and Family Health Services there is an excellent website for the Utah Registry of Autism and Developmental Disabilities. Utah Dept of Health & University of Utah School of Medicine Dept of Psychiatry obtained a grant from the CDC in 2003 to collect & share information about numbers of individuals with autism and to measure change. They outline where services are available in Utah. There appears to be an extensive network of programs throughout the state, various schools & lists of resources and names where parents can go to get help. Excellent information about various topics: clinical assessment, articles, patient education, etc. They publish a newsletter; the last one being in Spring 2005.

Utah Parent Center: www.utahparentcenter.org is a nonprofit, federally funded Parent Training and Information Center for the state of Utah. They provide parent training to parents of children with various disabilities on topics such as: IEP process, constructive communication, transitioning to adult programs. They have information on autism at their website. It is a great resource for parents that provides information on many things such as IDEA, Disability Resource Book, acronyms, etc. There is very nice information. There is a list of contact people: director, administrators, trainers. There is the Carmen B. Pingree School for Children with Autism. I've contacted Pete Nicholas, Ph.D., Director to ask questions.

The Registry of Autism & Developmental Disabilities has a variety of other useful website links:

<http://health.utah.gov/autism/Help.htm#HCProviders>. One is www.dotolearn.com that has materials and ideas on how teachers can work with children with autism. FASD Toolbox for Teachers – Great! I bookmarked this under autism. Another material site is

<http://resources.kaboose.com/games/online.html> that has great games, crafts, etc.

They have a research program at University of Utah School of Medicine through Child & Adolescent Psychiatry. They have Social Skills intervention groups for school age & young adult.

Washington: Senate Bill 5311 passed, approved by the governor in April 2005"

"The Caring for Washington Individuals with Autism Task Force was created by Senate Bill 5311 during the 2005 Legislative Session to study and make recommendations to the legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the state. The Department of Health is the lead agency in providing staff for the work of the task force. Recommendations on how to best prevent, identify, treat, and accommodate the needs of individuals with autism and their families will be completed and submitted to the appropriate policy and fiscal committees of the Legislature and the Governor by December 1, 2006."

There is a webpage through the Dept of Social & Health Services; Division of Developmental Disabilities. They provide good fact sheets on incidence & waivers. There are extensive services throughout the state.

Wyoming: Nothing