

Nevada Autism Summit Report – February 2006

Appendix C

Nevada Autism Summit Participant Data

- Values & Principles
- Recommended Actions

**Nevada Autism Summit
 Participant Data**

Values & Principles

KEY		
#✓	=	Number of priority votes
Agreement:		
H	=	High (15 or more priority votes)
M	=	Moderate (8-14 priority votes)
L	=	Low (fewer than 8 priority votes)

Birth-Five

#✓	Value/Principle	Agree
28	Every child/family deserves evidence-based, team-driven support & treatment as soon as ID is made	H
22	Every family deserves accurate, early ID & DX with appropriate referrals for any child who presents a concern to parents	H
14	Nevada will create a broad social education system to ensures all children ages 0-5, & their families are empowered with appropriate timely assessments & services for PDD/ASD	H
12	Every Nevadan deserves a sufficiently funded Autism center that provides transdisciplinary team services that are family/team centered as they relates to PDD/ASD	H
3	Every child with PDD deserves continuity of support and treatment across their age span and across the various agencies they encounter	M
1	Every Nevadan should have exposure and access to education and outreach information specific to child development and PDD	M

School Age

21	School systems are supportive of high quality teacher preparation, based on research-based practice & resulting in teachers' knowledge of best practices across the lifespan	H
14	Children with PDD/ASD have the right to appropriate & meaningful services based on individual needs to achieve full potential	H
12	Children with PDD/ASD have a right to well trained professionals	H
7	A freedom from prejudice in the public school system that recognizes all children with PDD/ASD can learn and other children can learn from them	H
4	Children with PDD/ASD have a right to inclusion within the school & community, as appropriate	H
3	Each community should have equal access to resources, including active parent involvement	H
2	Children with PDD/ASD deserve to be respected, to feel good about themselves, and to achieve quality of life.	H
2	Multi-agency collaboration to value complementary approaches and void "ownership" by one field	H

Transition

32	Effective transitions require proactive person/family centered planning, comprehensive assessment; collaboration/coordination of supports/services; monitoring/eval by stakeholders	H
27	Individuals with PDD/ASD have the right to live in the most integrated setting as independently as possible, realize individual goals & use their skills in their adult life & community	H
0	Transition is a process that impacts quality of life of individuals with PDD/ASD & their families	H

Adult

20	Range of employment opportunities & choices with opportunities for growth	H
8	Access to a range of life opportunities of the individual's choice	H

Intervention Options

18	All families should have = access to cost effective, efficient, evidence-based interventions in their local communities	H
15	All providers, parents, and professionals who work with individuals with PDD/ASD deserve high quality, best practice, research based up-to-date information and education	H
8	Intervention should be available across the lifespan with concentrated effort toward early intervention	H
7	All NVs with PDD/ASD have an = right to evidence-based treatment from highly qualified professionals	H
3	Professionals have an ethical responsibility to fully disclose accurate & complete information about the efficacy of their interventions	H
3	Parents should be educated on how to make informed decisions about various treatment options to empower choice	H
3	All stakeholders need to be accountable to each other with respectful, open, and direct communication including valuing parent observations & nurture/support for service providers	M
3	Linking assessment with intervention both conceptually & chronologically is key to developing mutually agreed upon meaningful outcomes	M
1	All NVs with PDD/ASD have a right to comprehensive, needs-based approaches based on multi-disciplinary assessment across the lifespan	M
1	Families deserve access in a timely manner to highly trianed professionals & support providers, including MDs, psychologists, teachers, therapists, etc.	M
0	All professionals will be held accountable for effectiveness of their services & must be able to show supporting data	H

Social Skills

25	Social & personal skills will be developmentally appropriate across the lifespan, family focused, and culturally sensitive for indivuals with PDD/ASD	H
17	Social/character building skills should be a part of every child's educational curriculum	H
6	Persons with PDD/ASD have the right to safe relationships with family, peers, community proviers, authority figures, coworkers, mates & the general public	H
5	Persons with PDD/ASD have the right to meaningful relationships to the extent that they are comfortable	H
4	Persons with PDD/ASD are, inherent to their disability, in need of social skill & relationship building assistance	H
3	Persons with PDD/ASD are sexual buings & hve the right to appropriate sexual education across the lifespan	H

Assistive Technology

24	Recommendations will take into account individual needs & preferences & will result in implementaion of an action plan	H
3	Access to appropriate AT to promote communication, social skills, independence, & quality of life across settings, throughout the lifespan	H
3	Ongoing education & training in the supported & functional use of AT to increase quality of life across settings, for individuals with PDD/ASD	H

Screening/Child Find

25	All children deserve the earliest possible & ongoing screening, sensitive enough for early ID of the full range of PDD/ASD, regardless of SES	H
8	Community collaboration across state, local, & federal systems to increase the efficacy of ID & services to children & support of families	H
2	All children deserve greater societal awareness of PDD/ASD	M

Employment

22	Individuals with PDD/ASD will have access & opportunity to integrated employment of choice with respect & dignity	H
5	Individuals with PDD/ASD will become productive members of the community through the utilization of best practices in ongoing assessment, training, education, and support	H
0	The community will derive economic & social benefit from investing in employment of individuals with PDD/ASD	H

Financial Issues

24	Effective early ID and intervention is inherently cost effective when compared with long term costs associated with delay in those services	H
5	Levels of service for individuals with PDD/ASD will be dictated by need rather than by financial constraints	H
5	State approved service providers for individuals with PDD/ASD will be paid in an immediate fashion encouraging a continuous & quality supply of providers	H

Assessment Across the Lifespan

24	Assessment should be accurate, thorough, relevant, accessible, and timely by qualified & competent professionals	H
5	The bridge between assessment, treatment, and outcome must be meaningful to the person with PDD/ASD and the family	H
2	Since development is ongoing/ever changing, the need for meaningful ongoing assessment across the lifespan is essential for all individuals with suspected & diagnosed PDD/ASD	H

Medical/Health Issues

17	Insurance should not drive the quality of services	H
11	Families & individuals have a right to easily accessible objective information about traditional, new, and alternative treatments	H
1	Links between physical & mental health are important considerations for individuals, parents, and members of the community	H
1	Diagnosis of PDD/ASD does not preclude the existence of other conditions & health needs over time	M
1	All stakeholders should be aware of preventative measures that must be taken to avoid development of secondary conditions	L
0	Families & individuals have a right to medical & health information beyond a label & should be empowered to make healthy life choices	M

Housing/Independent Living

18	Individuals with PDD/ASD will be provided with choice to ensure = access, safe, and healthy living arrangements in their community utilizing a person/family centered process	H
12	Individuals with PDD/ASD will be provided ongoing support & monitoring by trained individuals needed to exercise their choice and level of independence	H
1	Individuals with PDD/ASD have the right to the same quality of life as everyone else without discrimination	M

Professional Preparation

24	All persons with PDD/ASD are entitled to have qualified & trained professionals & paraprofessionals in the area of PDD/ASD	H
6	Families & persons with PDD/ASD deserve to have ongoing support & education	H
0	We are responsible to provide a positive school & community environment	M

0	We honor our special educators, professionals, & paraprofessionals who focus on the abilities of persons with PDD/ASD	M
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Post-Secondary Education

19	Individuals with PDD/ASD deserve all the resources & supports necessary to access post-secondary education successfully: college/university; and vocational training	H
5	Individuals with PDD/ASD have a right to transition planning & implementation based on individual needs, including self-advocacy, to prepare them for successful adult life	H
3	Individuals with PDD/ASD deserve the supports necessary to help them attain self-determination, and to achieve independence & quality of life	H
1	Individuals with PDD/ASD have a right to seamless transition from secondary to post-secondary services	M
0	The community, including the legal system, needs to be aware of the impact of PDD/ASD on behavioral & societal issues	M

Legal Issues

15	Individuals with PDD/ASD have the legal right to participate in inclusive educational & recreational programming with adequately trained professionals	H
12	Meaningful parental participation in the development of IFSPs, IEPs, and other service plans	H
0	All children need a timely & thorough evaluation & eligibility determination	H

Recommended Actions

Birth-Five

#	Recommendation/Action	Agree
30	NV will require all health insurance companies operating within the state to cover assessment, treatment, case management, program planning & parent training for children with PDD/ASD including Medicaid/Medicare, at the same rate of co-pay and level of service as other covered conditions	H
16	Nevada Medicaid will create a children's waiver to fund home & community based services that are evidence-based	H
11	A Nevada Autism Center will identify evidence-based assessment & services, implement broad based public & professional education on PDD/ASD, develop a centralized referral system & provide family/team centered services to every Nevadan affected by PDD/ASD	H
10	NV legislature will mandate & fund a community based Autism Center with and Autism czar to direct interagency collaboration & continuity of services across the lifespan with regard to children & families impacted by the diagnosis of PDD/ASD	H
9	Codes for PDD/ASD treatment need to be added to Medicaid through an assembly bill	H
4	Mandatory screening starting at 18 months	H
4	Close the gap between voiced parental concern and initiation of services	M
0	NV legislature will mandate an annual developmental screening with items specific to PDD/ASD, administered by pediatricians & family practitioners in every well child visit from 0-5	H
0	Funding for 2 Autism Centers that would provide parent training, professional development, certification, & services based on best practices as written by the NV DOE and BEIS	H
0	Education for everyone on developmentally appropriate & individualized treatment based on best practices as written by the NV DOE and BEIS	H

0	Support continuity for transition between 0-3 and 3-5 services	H
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School Age

17	NV will move forward with implementation of '211' information system to coordinate referrals	H
13	All general educators, support staff, and community providers will be trained to support children with PDD/ASD	H
11	Teachers will be supported to become appropriately trained to provide services, across all age levels, to meet individual student needs and given freedom to design curriculum to meet student needs	H
9	NV will train/hire enough highly qualified teachers to teach all students with PDD/ASD	H
4	Provide disability awareness activities in general education curriculum in order to develop a culture that values diversity	H
3	Parents will have access to on-going training & support	H
3	All children will be trained in character building skills	H
2	School staff & families will be informed about available resources	H
1	NV will devote sufficient resources to ensure early and accurate ID/diagnosis	H
0	Children with PDD/ASD will be included in the community when appropriate	H
0	Agencies will work together and take responsibility for 'warm hand-offs' - coordinated services	M

Transition

28	Increased training of professionals, parents, teachers in the aspects of social skills, transition options, and the "how to" regarding transition	H
17	Facilitate supported inclusion across home, school, and community settings	H
14	Transition planning across the lifespan must reflect continuity	H
8	Hold existing agencies accountable	H
8	Ensure provision of resources that promote choices & options that result in meaningful outcomes	H
6	Promote independence & self-advocacy	H

Adult

15	Access to a full range of education, training, & employment support by personnel knowledgeable of PDD/ASD	H
7	Development of community living opportunities for people with PDD/ASD	H
3	Appropriate person-centered assessment that leads to successful employment of individual's choice	H
3	Availability, access, and community support for social, housing, transportation, leisure, recreation, and enriched community living opportunities for people with PDD/ASD	H
3	Family support throughout the lifespan of the individual with PDD/ASD	H
1	Community awareness/education about PDD/ASD	M
0	Community awareness/education in hiring people with PDD/ASD	M

Intervention Options

19	All NV state insurance providers will provide coverage for a range of research-based intervention options at the intensity determined by the individual's needs	H
12	Develop comprehensive system by which individuals/agencies can be trained to provide accurate & authentic diagnoses	H
5	NV legislature will fund an autism waiver to encompass evidence-based interventions, family & individual counseling, family support, respite services, speech, OT/PT, & AT	H
6	Recruit/build large pool of qualified personnel & support them in both financial & non monetary ways to improve retention	M
5	Create mechanisms through which stakeholders will be accountable to each other (e.g., document through an Autism Center)	H
4	Across lifespan, families & individuals with PDD/ASD will have access to case-management, including all relevant professionals and agencies	M
3	State will provide funding for continuing education & training of professionals who work with people with PDD/ASD	M
3	Provide funding to conduct systematic reviews of available outcome evidence	H
3	Conduct research related to intervention options & models of service delivery that may increase accessibility, reduce cost, & maintain consistency of services	H
2	Centralized system to disseminate information on educational opportunities, referrals to professionals, & available research on treatment options	H
2	Guidelines on state standards of training professionals in evidence-based practice will be established	H
2	NV legislature will fund the autism waiver for individuals with PDD/ASD based on need rather than income	M
2	Develop & use technology to disseminate information related to intervention options and resources to all stakeholders	M
1	NV will recruit professionals across disciplines to serve our burgeoning PDD/ASD population	H
1	NV legislature will provide a funding source available to persons with PDD/ASD who do not meet the autism waiver requirement, but who demonstrate need	M
0	NV legislature will implement a licensing, certification, and registration system for professionals providing services to ensure highly qualified & trained professionals are providing evidence-based services	H
0	Highly qualified & trained professionals will provide evidence-based services	H

Social Skills and Sex Education

28	Autism Center will provide training/support for mentors/support persons in school, home, work & community, life skills & relationship building training to agencies providing services, training on safety & boundaries across lifespan; training to emergency response personnel, attorneys, judges re: special characteristics of persons with PDD/ASD	H
23	Personal/social skills training will be embedded from early intervention through adulthood in health/hygiene, body boundaries, sexual development, safety, social/interpersonal skills	H
5	DOE will develop a comprehensive life skill/relationship building & sex ed curriculum for persons with PDD/ASD. This curriculum will be developed through a team that includes educators, specialists in PDD/ASD, parents, and community agency eprsonnel	H
5	Social/Life skills training & pragmatic communication skills should be part of the IFSP/IEP and other service plan of every person with PDD/ASD	H
3	NV will require an embedded school wide curriculum for all students for character building that includes social skills, personal responsibility, citizenship, & disability awareness	H
2	Access to support & training from highly qualified individuals in PDD/ASD and social/sexual development	H
0	NV Higher Ed DRCs will provide training/information to faculty & staff working with/teaching adults with PDD/ASD	H
0	All Nevadans will be made aware, through public awareness media tools, that persons with PDD/ASD have social skills deficits	M

Assistive Technology

25	Provide sufficient funding/resources to appropriately provide AT to Nevadans with PDD/ASD, recognize communication devices as medically necessary, enhance training, expertise & resources to BEIS & Voc Rehab, intense education & training for medical funders & providers concerning need for & benefits of AT for persons with PDD/ASD	H
7	Educate families, schools, professionals, agencies as to the scope & implementation of AT, through web-based services, university programs, professional development; recruit/train professionals to gain knowledge & expertise in the assessment & delivery of AT specific to the needs of individuals with PDD/ASD	H

Screening/Child Find

21	All pediatricians, to acquire & maintain licensure, will be required to receive training on PDD/ASD & in administration of screening/asst tools and appropriate referral sources	H
8	All licensed child care providers, prior to dismissal of a child for behavioral concerns, be required to screen & refer to appropriate community resources	H
3	Professional & research development & refinement of specific screening tools & training in the use of those tools by all providers, school personnel, etc.	H
1	Eligibility criteria need to be more inclusive to reach all children throughout the PDD/ASD spectrum	H

Employment

24	Strengthen availability & quality of services related to: pre-employment skill development; ID of key interests/strengths; opportunities for hands-on experience; post secondary ed; prep for employment environment; integrated employment options with = pay for = work	H
6	Require cross agency coordination of comprehensive employment services for individuals with PDD/ASD	H
4	Provide resources for professional development training specific to PDD/ASD for service providers working in employment services	H
0	Provide resources to families of persons with PD/ASD for education & training related to the employment process	H

Financial Issues

20	Pass a bill requiring that: all agencies providing services to persons with PDD/ASD be required to publicly report actual needs & associated costs to meet those needs to NV legislature; private insurance & Medicaid will meet the full financial needs associated with persons with PDD/ASD	H
18	NV will fund evidence-based services to meet the full range of needs associated with individuals with PDD/ASD	H
11	NV will create a funding mechanism for persons with PDD/ASD that includes, but is not limited to: sliding pay scale; 'money follows the person credit card system; state funded buffer system that interfaces with Medicaid & private insurance companies	H
1	Enhance existing state approval process for qualifying service providers based upon best practices to meet the full range of services for persons with PDD/ASD	H

Assessment Across The Lifespan

18	NV will provide funding for professional training across disciplines responsible for ID, assessment, and diagnosis of persons with PDD/ASD	H
4	NV will fund & support a multidisciplinary team approach to meaningful assessment across the lifespan of persons with PDD/ASD	H
3	Develop guidelines for meaningful assessments to address barriers to personal outcomes (quality of life, social experience, recreation, education, work) for persons with PDD/ASD	H
3	Develop functional outcomes assessment to determine treatment efficacy	H

Medical/Health Issues

22	Develop online clearinghouse with coordinated information re: health practices including medications, supplements, nutrition, and diets	H
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4	To maintain continuity of care, previously established medical and other insurance options, such as dental & health, can be maintained throughout the lifespan	M
2	Service providers will be 'up front' in communicating with families, provide proactive care, know limits, and refer elsewhere when necessary	H
2	Comprehensive medical & psycho-social history should be part of every provider's intake	L
1	Systematic review of available research on vaccine safety should be conducted	L
0	Educators should receive training to increase awareness of signs of PDD/ASD & associated health problems	H
0	Educate third party payers re: health needs and options	M

Housing/Independent Living

20	NV will evaluate housing options & project & meet housing needs to increase choice	H
6	NV will designate agent to research models of other states housing options, with best practices & develop the practices within NV	H
2	A system to teach prerequisite skills necessary to access independent living arrangements	H
0	NV will allocate resources for additional qualified personnel to meet the rising PDD/ASD population	H

Professional Preparation

15	Continuing education in PDD/ASD should be required to maintain regular ed, special ed, and administrative credentials and licensing	H
8	Autism Center will promote NV as 'place to be' for cutting edge & best practice service provision and professional training in PDD/ASD	H
4	NV will improve recruitment of special services personnel across the lifespan by providing: special loans to subsidize home purchases; reasonably competitive salaries; signing bonuses connected to years of service; college tuition waivers; development of sabbatical program (for special ed teachers)	H
3	NV legislature should increase the pay scale for special ed teachers	M
1	NV will promote an endorsement or license for paraprofessionals across the lifespan working with persons with PDD/ASD; these paraprofessionals should receive benefits, college level studies, and a pay scale reflective of their training level	H
1	DOE or school districts will provide autism summits for special ed teachers, aides, paraprofessionals, professionals across the lifespan to promote networking, observation of each other, & support for each other as opposed to "training"	M
1	Provide ongoing public campaign to honor those working with special needs individuals	M
0	Provide high quality induction/mentoring to new teachers & paraprofessionals across the lifespan	M
0	Special education classrooms must be within the ebb & flow of a school	L

Post-Secondary Education

16	Transition planning should include instruction in all skills relevant to success in working, living, and post secondary education	H
11	Transition planning must be implemented during the middle school years, or earlier if appropriate	H
3	Adults with PDD/ASD will be assisted in accessing appropriate post-secondary education services & supports based on individual needs	H
2	Training in evidence-based practices should be available for professionals who work with persons with PDD/ASD in post secondary settings	M
1	Case-management supports will be available for adults with PDD/ASD to access needed post-secondary educational services & supports	H
0	Post secondary professionals should be trained on the characteristics & needs of individuals with PDD/ASD	H

Legal Issues

17	Provide incentives to attract & retain highly qualified professionals & support staff	H
3	Increase support & training for professionals working with persons with PDD/ASD	H
3	Expand support to parent advocacy & non-profit groups providing services to persons with PDD/ASD	H
2	Increase parental awareness of available advocacy resources, the law, and parents' rights	M
2	Increase interagency collaboration to support inclusive programming	H
2	Provide families of persons with PDD/ASD education, training, mentoring, & broader range of information on available services	H
2	Provide additional resources, personnel, & appropriate funding to eliminate waiting lists	H
1	NV will develop systems for legal concerns to address self-advocacy & awareness of legal issues	M