







2008 Report

Of The Nevada Autism Task Force

An Action Plan For Nevada's Legislators And Policymakers

Complete Document & Recommendations
Appendix A-G in separate documents

Ralph Toddre, Chairman

Nevada Autism Task Force

Addressing issues across the lifespan

July 28, 2008

Legislators and Policymakers:

Has the incidence of Autism reached epidemic proportions? During the decade of the 1990's, the number of Americans with Autism grew 13 times faster than the nation's population. By all accounts, the growth rate has accelerated over the past eight years. It is now estimated that 1 in 150 newborn babies will be diagnosed with Autism Spectrum Disorder.

What have we done in Nevada to respond to this epidemic? The short answer is, not much… yet.

Left untreated, Autism is a disease that breaks up families, sentences individuals to a life of dependency, isolation and discrimination. And costs society billions of care dollars every year—90 percent of which are spent during a person's adult years.

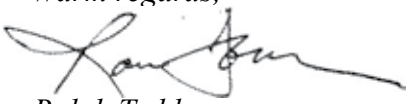
And so, what can be done? The great news is that proven and emerging therapies can ameliorate the effects of Autism, especially when they are brought to bear in a child's early years. An early investment in therapy can yield a lifetime of benefits for a person with Autism—and for society.

To their credit, the 2007 Nevada Legislature, Governor Jim Gibbons and First Lady Dawn Gibbons recognized the opportunity that exists in fighting Autism. They committed both dollars and political capital to establish an Autism pilot program, and an Autism Task Force to study and make recommendations addressing the Autism crisis in Nevada.

Over the past 12 months, a lot of very dedicated people have lent their expertise and collaborated to develop this Autism action plan for Nevada. I would particularly like to thank the members of the Task Force, the staff of the Office of Disability Services, and the many members of the public who served on our subcommittees.

By reading this report and taking action, you give recognition to the thousands of Nevada's citizens, and their families, who are fighting the constant battle against Autism. Thank you for honoring them!

Warm regards,



Ralph Toddre
Chairman

Nevada Autism Task Force
Addressing issues across the lifespan

Contents

Enabling Legislation

AB 629 of the 2007 Nevada Legislature

From Section 40…

The Nevada Autism Task Force is hereby created to study and make recommendations to the Governor and the Legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the State.

The Task Force shall:

(a) Hold not more than six open meetings each year where parents, educators and experts in the field, among others, can present testimony and information to the Task Force;

(b) Review the available literature and consult with experts to gain an under standing of the causes of the disorder and its incidence in Nevada;

(c) Assess the availability of services currently provided for early screening, diagnosis and treatment of the disorder;

(d) Review the effectiveness of programs and services currently provided to individuals with autism and their families; and

(e) Review other issues and concerns that the Task Force believes would be helpful in arriving at sound policy recommendations.

The Nevada Autism Task Force is hereby created to study and make recommendations to the Governor and the Legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the State.

The Nevada Autism Task Force shall complete its review and submit its findings and recommendations to the Governor and to the Director of the Legislative Counsel Bureau for transmittal to the appropriate legislative committees on or before August 1, 2008.

Task Force Members

Appointed according to statute

The Nevada Autism Task Force consists of 14 members, who were appointed as follows:

- Senator Warren Hardy, appointed by the Majority Leader of the Senate
- Senator Bernice Mathews, appointed by the Minority Leader of the Senate
- Assemblyman James Ohrenschall, appointed by the Speaker of the Assembly
- Assemblywoman Francis Allen, appointed by the Minority Leader of the Assembly
- Jan Crandy, Korri Ward, and Dr. Elizabeth Moore – parents of children with Autism, appointed by the Governor
- Ralph Toddre, Dr. Pat Ghezzi, Dr. Matt Tincani, Flo LaRoy – representatives of the Autism Coalition of Nevada, appointed by the Governor
- Mary Liveratti, Designee of the Director of the Department of Health and Human Services
- Cynthia McCray, Designee of the Superintendent of Public Instruction
- Dr. Johanna Fricke, Expert in the field of early intervention services

About This Report

The compilation of this report required the efforts of more than SIXTY people. This team of parents and professionals collaborated and worked very hard to bring you this valuable planning tool.

We approached the challenge of this report by dividing Autism issues into seven different categories, as follows listed alphabetically:

- Best Practices
- Education
- Financing Comprehensive Systems of Care
- Screening and Diagnostics
- Training, Certification and Applied Behavior Analysis
- Transition, Employment and Community Inclusion
- Workforce Development

The Executive Summary outlines Nevada's eleven most critical priorities.

Each category had its own subcommittee of 10-15 members, made up of experts and stakeholders from the community and members of the Task Force. Each subcommittee held public meetings and conducted substantial research between each meeting. Subcommittee discussions included consideration of reviewed, evidence-based research, testimony heard from experts, stakeholders and public input. The seven subcommittees each compiled a report with recommendations on their topic, and submitted it for editing and approval by the Task Force.

In total this report outlines 146 recommendations, and they are organized by the seven different categories listed above. Each report addresses issues and the findings to support the necessary recommendations. The full report includes each subcommittee report in it's entirety with their individual recommendations listed at the end of each section. The full report also includes a section listing the combined 146 recommendations for quick reference. We encourage use of the complete document as a starting point for future strategic planning. And believe it gives an overview of the information gathered and reviewed.

The Executive Summary

The Executive Summary outlines Nevada's eleven most critical priorities, which we view only as initial steps in implementing the Autism Task Force Action Plan. The Executive Summary and Recommendations for Immediate Action list is designed to give readers an overview of the key recommendations made by the Nevada Autism Task Force.

Executive Summary

Individuals with Autism Spectrum Disorders (ASD) are Nevada citizens who deserve to live the same quality of life as other citizens, regardless of their age, race, ethnicity, or geography.

Passing legislation to mandate insurance coverage to provide for screening, diagnosis and Autism-specific treatment such as Applied Behavior Analysis (ABA) is the priority of this Task Force.

Autism Spectrum Disorders typically affect a person throughout their life. However, for a child with ASD, an early diagnosis and intense intervention can mean the difference between living an independent life or a life dependent on the support of others. Research has proven 47% of the children who do receive early intervention using Applied Behavior Analysis (ABA), 30 to 40 hours per week, go on to lead normal lives. While 90% who do not, go on to need a lifetime of care. One of the unique impacts of treatment is the improvement in cognition. A child with an I.Q. in the mental retarded range can demonstrate I.Q.s within the normal range or higher, after receiving intensive levels of treatment. Everyone deserves the opportunity to reach their full potential.

Families receive little help to provide for the high expense of treatment, less than 6% of individuals with ASD in Nevada receive funding from state programs. Included is the Office of Disability Services Autism Intervention Program, which is in danger of not being funded after June of 2009. This program was funded through AB629 with long-term intent. Legislation must make this program permanent with yearly case growth.

Most insurance companies exclude ASD and Autism-specific treatments including ABA, which has been endorsed by the U.S. Surgeon General and other government and scientific organizations. Medicaid and Nevada Check Up also do not provide coverage for ABA or other autism-specific therapies.

It is imperative that Legislators create a public-private partnership for provision of care. Autism Spectrum Disorder is the fastest growing developmental disability affecting more children than AIDS, childhood cancer and diabetes combined. All of which are covered by insurance. Autism is a medical condition and Nevada's practice of allowing insurance companies to exclude coverage is discriminatory.

Passing legislation to mandate insurance coverage to provide for screening and diagnosis and Autism-specific treatment such as Applied Behavior Analysis (ABA) is the priority of this Task Force. The cost of this insurance reform is minimal and will have very little impact on the cost of health insurance premiums for the individual consumer.

By improving outcomes for children with ASD, insurance coverage will decrease the lifetime costs of providing services and will actually result in an overall cost savings to the state and it's taxpayers.

The practice of continuing to ~~exclude~~ insurance companies to prohibit coverage of treatment needed by Nevada's policyholders with ASD, insurance companies are effectively passing costs on to State programs.

The practice of continuing to allow insurance companies to prohibit coverage of treatment needed by Nevada's policyholders with ASD, insurance companies are effectively passing costs on to State programs, including Early Intervention Services, K-12 Education, Medicaid, Mental Health and Developmental Services, Independent Living Services and Vocational Rehabilitation. Combined, these programs spend millions of dollars each year providing services that insurance companies refuse to cover.

Due to the lack of qualified providers of Autism-specific treatments, stakeholders continue to spend dollars out-of-state for services. Nevada needs to make an investment in professional development to grow a workforce to serve individuals with ASD. Nevada has only 26 Board Certified Behavior Analysts to develop quality ABA treatment plans. Nevada educators do not receive adequate training and what does exist, is inconsistent across the state. Legislation must significantly increase funding to provide evidence-based programs to students with ASD and the professional development to implement them.

The importance of an early diagnosis cannot be stressed enough, the best outcomes happen when treatment begins by the age of 3. Children continue to go undiagnosed in Nevada due to the lack of qualified professionals, informed pediatricians and Nevada Early Intervention Services (NEIS) limited infrastructure and professional development.

The price tag for a lifetime of care for one untreated person with Autism Spectrum Disorder and intellectual disabilities could be as high as $6 million. Most of the expense is in adult care and falls on the state. ASD has reached an epidemic status affecting 1 in 150 children born today. As these children grow up, Nevada is unprepared to adequately serve them as adults. Adult services need to include transition support, employment and community inclusion.

Nevada has a duty of care for the health and welfare of its citizenry. The needs of individuals with Autism Spectrum Disorders (ASD) have gone unmet in Nevada for years, and if those needs continue to go unmet, the state may be forced to fund the high cost of litigation related to the silent suffering of children and families faced with autism, who are not receiving basic services.

Incidence of Autism Spectrum Disorder

There is an estimated 5,176 Nevadans ages 0-21 years old with Autism Spectrum Disorders.

- The Center for Disease Control and Prevention (CDC) estimates 1 out of every 150 children are being diagnosed with ASD.
- Using the CDC prevalence rate of 1 in 150 children, there is an estimated 5,176 Nevadans ages 0-21 years old with ASD. Based on 776,333 age specific population of 2005.

What is Autism Spectrum Disorder?

- Autism Spectrum Disorder (ASD) is a neuro-biological medical condition associated with unique abnormalities in brain development. It is not a mental health or behavioral disorder.
- ASD is characterized by impairments in three domains: social interactions, language and communication, and repetitive behaviors and preoccupations.
- ASD varies in severity of symptoms and may include drastically lower IQ, a total lack of verbal communication, self-injuring behavior, and a variety of co-occurring medical conditions.
- The manifestations of ASD can differ considerably across children and within an individual over time.

This Recommendations for Action list is designed to give readers an overview of the key recommendations made by the Nevada Autism Task Force. Each subcommittee section lists additional ideas generated during Task Force and sub-committee discussions. Task Force discussions included consideration of reviewed, evidence-based research, testimony heard from experts, stakeholders and public input. We encourage use of the complete document as a starting point for future strategic planning. And believe it gives an overview of information gathered and reviewed.

Recommendations for Immediate Action

The Nevada Legislature is asked to ensure that Autism Spectrum Disorder is treated as any other medical condition, by passing insurance legislation.

1. The Nevada Legislature is asked to ensure that Autism Spectrum Disorder is treated as any other medical condition, by passing insurance legislation that will:

a. In general, require health insurance policies and the medical assistance program to cover the screening, diagnosis and treatment of Autism Spectrum Disorders in individuals less than 21 years of age. Applies to policies offered, issued, or renewed on or after July 1, 2009, to groups of 51 or more employees. Include all insurance programs in Nevada, including self-funded and self-insured plans.

b. Benefit limits – Coverage for evidence-based behavioral therapies are subject to a maximum yearly benefit of $36,000 but no lifetime benefit caps or visit limits. After December 30, 2011, the maximum yearly benefit will be adjusted for inflation.

Coverage is subject to co-payment, deductible, coinsurance provisions, and general policy or program limitations and exclusions to the same extent as other medical services.

c. Authorized treatment – The treatment of Autism Spectrum Disorders includes the following medically necessary care identified in a treatment plan:

i. Prescribed medications and any test needed to determine their effectiveness;

ii. Psychiatric care;

iii. Psychological care;

iv. Habilitative and rehabilitative care, including Applied Behavior Analysis (ABA);
and

v. Speech therapy, occupational therapy, and physical therapy.

vi. Allow for a Physician or Psychologist or qualified Masters-level professional to develop the treatment plan for autism spectrum disorder. An insurer may review the treatment plan once every six months, unless the insurer and physician or psychologist agree that more or less frequent review is necessary.

vii. As a cost savings measure, allow reimbursement of Masters-level, licensed therapeutic care professionals, as well as paraprofessional therapists when working under the supervision of a Masters-level (or greater), licensed professional.

viii. Providers – The Nevada Psychology Board, in consultation with other appropriate state agencies, will set standards for behavior specialists, a newly recognized group of service providers.

Insurers are required to contract with and accept as participating providers Autism service providers enrolled in Nevada's medical assistance program who agree to accept the payment terms and conditions that apply to the insurer's other participating providers.

ix. Review—If an insurer denies a claim for diagnosis or treatment of Autism Spectrum Disorders, an insured can seek an expedited internal review followed by an expedited independent external review. An insurer or an insured may appeal to a court an order of an expedited independent external review. While the appeal is pending, an insurer must pay for services that have been authorized or ordered.

The Nevada Legislature is asked make permanent the Autism intervention program currently funded in budget account 3266 in Office of Disability Services.

2. The Nevada Legislature is asked to pass legislation that makes permanent the Autism intervention program currently funded in budget account 3266 in the Office of Disability Services. This was the program funded through AB 629 last session.

3. The Nevada Legislature is asked to pass legislation that will:

a. Require Nevada pediatricians, during their regular developmental screenings or well-baby checks, to screen for Autism Spectrum Disorders twice by the child's second birthday, as recommended by the American Academy of Pediatrics.

b. Require the Modified Checklist for Autism in Toddlers (M-CHAT) screening to be conducted by providers of Early Intervention Services ("providers"), on all applicant children at 18 months of age, or at intake if the child is older. All children who fail this screening should be given an Autism-specific assessment by a qualified multi-disciplinary team using a battery of assessment tools supported by current research, including at least one tool that is based upon parent input. If this assessment identifies a child as displaying evidence consistent with Autism Spectrum Disorders, require that (NEIS):

The Nevada Legislature is asked to pass legislation that requires screening and diagnosis of ASD.

i. Advise the parents that the child has been identified as being eligible for services within the category of Autism Spectrum Disorders.

ii. Advise the parents that, to receive insurance coverage or to qualify for other resources, a formal diagnosis may be needed.

iii. Refer the parents to a professional for diagnosis, which may be funded by the agency or the family.

iv. Refer the parents to support groups.

The Nevada Legislature is asked to pass legislation that will enhance professional development specific to ASD.

4. The Nevada Legislature is asked to pass legislation that will improve the State's ability to serve citizens with Autism Spectrum Disorders through enhanced professional development specific to Autism Spectrum Disorders, to include:
    a. Adopt standards and benchmarks established by the Autism Task Force. Any adopted benchmarks and standards should apply to:
        i. Agencies providing Early Intervention Services
        ii. Public schools in Nevada
        iii. Nevada System of Higher Education
        iv. Vocational Rehabilitation
    b. Fund enhanced professional development across systems.
    c. Develop regional multidisciplinary crisis intervention teams for crisis intervention and support.

The Nevada Legislature is asked to pass legislation that ensures existing service systems address the needs of adults with ASD.

5. The Nevada Legislature is asked to pass legislation that ensures existing service systems address the needs of adult Nevadans with Autism Spectrum Disorders. The bill should require the following programs to establish service level and outcome benchmarks, and an action plan for reaching those benchmarks:
    a. School districts, relative to transition plans into post-secondary education or employment.
    b. Vocational Rehabilitation
    c. The Office of Disability Services Personal Assistance Services program.
    d. Mental Health and Developmental Services and their contractors.

The Nevada Legislature is asked to ensure paraprofessionals working with students with ASD meet competencies and receive pay based on a tier system.

6. The Nevada Legislature is asked to pass legislation that ensures the paraprofessional aides serving students with Autism Spectrum Disorders in special education programs are appropriately qualified. The bill should:
    a. Establish a certification process for paraprofessional aides.
    b. Establish guidelines for the needed knowledge and demonstration-in-practice competencies.
    c. Establish a classification system based upon competency levels.
    d. Develop and set paraprofessional salary levels, based on a tier system of meeting defined competencies.
    e. Provide for paraprofessional aides to be counted as a separate position in school funding calculations.
    f. Requires the addition of a definition, within the Nevada Administration Code, of "appropriately trained" which applies specifically to paraprofessionals who work with students with Autism Spectrum Disorders.

The state will develop a 10-Year Strategic Plan to address Nevada's ASD workforce needs.

7. The Nevada Legislature is asked to pass legislation that requires any State agency or public schools serving individuals with Autism Spectrum Disorders:

a. Adopt and implement the Autism Task Force Best Practices guidelines included in the full report.
b. Provide an on-going parent training program, the specifics of which will be developed by the Autism Task Force for consideration by the 2011 Nevada Legislature.

The Nevada Legislature is asked to pass legislation requiring any state or public schools to adopt the Autism Task Force Best Practices when serving individuals with ASD.

8. The Nevada Legislature is asked to pass legislation that:

a. Establishes a system for collecting and compiling longitudinal data on individuals with Autism Spectrum Disorders across early intervention services, elementary and secondary schools, vocational rehabilitation, and developmental services.
b. Requires the Division of Mental Health and Developmental Services, and the Office of Disability Services to include children with Autism Spectrum Disorders in their caseload tracking and projection data systems.

9. The Nevada Legislature is asked to pass legislation that pilots at least three projects to lower public school caseload size based upon the number of students with Autism Spectrum Disorder and the severity of their disabilities; ensuring the pilots would take place in Southern Nevada, Northern Nevada and Rural Nevada.

The Nevada Legislature is asked to pass legislation that continues the Nevada Autism Task Force.

10. The state will develop a 10-Year Strategic Plan to address Nevada's ASD workforce needs to include:

a. Increase Funding for ASD Programs in Critical Shortage Area.
b. Maintain Funding for Nevada's System of Higher Education at Parity with the National Average
c. Create Incentives for ASD Professionals to Stay in Nevada
d. Initiate Professional Training Programs that Target Adult Nevadans with ASD
e. Secure Federal Funding to Support Professional Training Programs
f. Increase Nevada's capacity to produce a sustainable workforce of behavioral analysts.

11. The Nevada Legislature is asked to pass legislation that continues the Nevada Autism Task Force until June 30, 2013, for oversight and future strategic planning.

Best Practices

Members of the Best Practices Subcommittee

Jan M. Crandy, Chair
Nevada Autism Task Force Member
Autism Coalition of Nevada, Southern Nevada Executive Director
SPAC, Strategic Plan Accountability Committee for Persons with Disabilities, Chair
Parent, Southern Nevada

Melanie Stevens
Staff

Committee Members

Francis Allen, Nevada State Assemblywoman

Diane Branson
Nevada State Health Division Autism Training and Technical Assistance

Johanna Selikoff Fricke, MD

Cynthia McCray
Clark County School District, Director, Low Incidence Disability Team

Debra Meinberg
Easter Seals, Southern Nevada

Randy Figurski, MS CC-SLP

Patrick M. Ghezzi, PhD, BCBA
Director, Behavior Analysis Program
Director, UNR Early Childhood Autism Program

Nicole Kalkowski
Parent, Southern Nevada

Ron Leaf, PhD
Autism Partnership

Erik Lovaas, President
The Lovaas Center for Behavior Intervention

James Ohrenschall, Nevada State Assemblyman

Valerie Soto
Parent, Southern Nevada

Nancy Sylvanie, PhD

Richard Thompson, BCBA
Carpe Diem

Matt Tincanti, PhD, BCBA
UNLV

Jennifer Van Tress
Washoe County School District, Assistant Principal, Moss ES & Caughlin Ranch ES

Estleen Westby
Parent, Southern Nevada

Best Practices

Executive Summary

The purpose of this section is to define and clarify Best Practices in providing appropriate and effective interventions for individuals with Autism Spectrum Disorders (ASD) and Autism-related disorders.

It is one thing to tout "best practices" and another thing to actually employ them. The term "best practices" encompasses a variety of treatment interventions, including practice guidelines and treatments that are effective and evidence-based. Best Practice should take place within a continuum of care that includes guiding principles, accurate data collection, screening, diagnosis and assessment, medical and therapeutic care, parent training, and the delivery of evidence-based treatment.

Best Practice should take place within a continuum of care that includes guiding principles, accurate data collection, screening, diagnosis and assessment, medical and therapeutic care, parent training, and the delivery of evidence-based treatment.

Evidence-based programs are programs that have been shown to be effective by scientifically rigorous evaluations. Evidence-based best practice programs should not be confused with programs that simply purport to represent best practice though lack the independent evaluations that validate their assessment of effectiveness. The vast majority of intervention and treatment as well as supervisory programs related to Autism Spectrum Disorders, (A.S.D.) have not been rigorously evaluated, however there are a considerable number of programs using the principles of Applied Behavior Analysis, (A.B.A.) that exemplify evidence-based best practice. Evidence-based best practice programs are not only effective in the services they provide, but, also, demonstrate a very good investment. As a result, public and private funding agencies are usually more inclined to fund evidence-based programs given the programs immediate return in effective outcomes and as a model for future quality program development.

Recommendations 1-16 provide a framework of support, resources and oversight to ensure Nevada state agencies, school districts and providers implement Best Practices when serving Individuals with Autism Spectrum Disorders (ASD).

There are an estimated 5,176 children with ASD in Nevada, these children are going to be adults in need of group homes or out-of-state placements if we choose to do nothing, now. ASD effects individuals across their lifespan. The impact on Nevada's future economy and those with ASD will be adversely effected, if Nevada chooses not to endorse evidence-based treatments and the funding to support them.

Evidence-based Practice

I. What is Evidence-Based Practice?

Evidence based practice refers to those interventions, treatments, and methodologies that are considered effective by the current autism research base and are therefore more likely to result in positive outcomes for students.

II. Evidence-Based Practice and Individuals with Autism

"Thus far, there is no one universally accepted and recommended treatment for autism. That is not to say that all treatments are equally effective. Deciding which treatment is appropriate for your child (student) can be an exceedingly difficult and stressful choice. The first question that must be answered before making this choice is: 'What standard should we use when evaluating treatments for autism?' **A treatment can only be deemed effective if it is based on sound, scientifically validated principles and supported by empirical data.** In simple terms, this means that treatments for autism must be backed by the same quality of research that we demand from other fields of science, such as medicine, chemistry and engineering." (Irwin, 2005)

In simple terms, this means that treatments for autism must be backed by the same quality of research that we demand from other fields of science, such as medicine, chemistry and engineering.

III. Characteristics of Evidence-Based Programs/Treatments for Individuals with Autism

Evidence-based programs for individuals with autism use data to evaluate effectiveness. Data are collected on an ongoing basis and reviewed frequently to make program changes. Evidence-based programs have explicit decision rules for how staff use data to make program changes.

Evidence-based practice involves the application of current research to the practice of treating others. Research to support evidence-based practice is published in peer-reviewed journals using direct observation and systematic measurement. Repeated demonstration of effectiveness is established through replication of intervention effects (Green, 1996). Anecdotal evidence is insufficient to establish an intervention's effectiveness.

Evidence-based programs have established and demonstrated validity through the use of experimental rigor and replication. Designs with high degrees of internal and external validity are used to systematically evaluate program outcomes. Both group-experimental (Campbell & Stanley, 1966) and single-subject (Kazdin, 1982) designs are employed. Confounding variables are actively controlled to reduce error variance. Anecdotal evidence and opinion is eschewed in favor of objective data.

Evidence-based programs have durable effects in "real world" settings. While desirable, studies in clinical, laboratory, and other highly controlled settings are insufficient to establish program efficacy. Evidence-based programs have demonstrated effectiveness in

school, home, and community settings, with stakeholders as active participants and agents of behavior change (Carr et al., 2002; Tincani, 2007).

Evidence-based practice involves critical evaluation by consumers. While publication in a peer review journal may add to our comfort, it offers no guarantee of soundness. Some journals are more rigorous than others, while some that show experimental rigor may lack clinical relevancy. One should bring a critical eye, thorough analysis, and good consumerism to every study one encounters, no matter how promising or intuitively resonant the findings. There is just too much riding on our treatment decisions not to do so. (Leaf, Taubman and McEachin, in press)

IV. The Federal Perspective on Scientifically-based Research

The No Child Left Behind (NCLB) Act of 2001 encourages and, in some cases such as Reading First, requires the use of instruction based on scientific research. The emphasis on scientifically based research supports the consistent use of instructional methods that have been proven effective.

To meet the NCLB definition of "scientifically based," research must:

1) employ systematic, empirical methods that draw on observation or experiment;
2) involve rigorous data analyses that are adequate to test the stated hypotheses and justify the general conclusions;
3) rely on measurements or observational methods that provide valid data across evaluators and observers, and across multiple measurements and observations; and
4) be accepted by a peer-reviewed journal or approved by a panel of independent experts through a comparatively rigorous, objective, and scientific review.

V. Guiding Principles of the Nevada Autism Taskforce

The Nevada Autism Task force believes it is critical for professionals charged with making decisions about methodologies and services for children with autism to:

- obtain, know and understand the scientific support for each approach;
- recognize the difference between an approach that has been scientifically validated and one that has not.

In addition, the Nevada Autism Task Force believes professionals endorsing a specific intervention for autism have an ethical responsibility to:

- accurately describe the research support of the intervention, or lack thereof;
- refrain from exaggerated claims of effectiveness when data supporting such claims do not exist;
- portray the method as experimental, if it is not yet validated as effective scientifically, and to disclose this status to key decision makers influencing the child's intervention.

Finally, it is important to note data exist in some cases which repeatedly lead to conclusions a particular methodology is ineffective or may be harmful. In such cases, the Nevada Autism Task Force believes continued utilization of resources on these approaches is at best ethically questionable, and at worst a significant waste of time, energy, money, expertise, and a child's potential to live a fulfilling life in least restrictive settings.

Best Practices for children address the following:

In Nevada, individuals with Autism Spectrum Disorders and their family members will be able to access an array of effective services which are considered Best Practice in their delivery to meet their functional and clinical needs across the life span.

- **Nevada children will be screened for ASD as young as current research enables.**
  - ✔ The American Academy of Pediatrics is recommending the administration of screening for ASD twice for all children by their second birthday.

- **Nevada children identified at risk for an ASD diagnosis will be immediately referred for further evaluation and intervention services (simultaneously).**
  - ✔ The importance of early, intensive intervention for children with autism cannot be overstated. Numerous studies have concluded outcomes are substantially more positive when the children begin receiving effective, intensive intervention as early as possible in life (including the potential to recover normal functioning such that an child with autism may become virtually indistinguishable from his peers) (eg Fenske, et al, 1985; Lovaas, 1987; Maurice, 1993; Perry, Cohen & DeCarlo, 1995). Furthermore, early, intensive, effective intervention offers the hope of **significant cost/benefit** reducing the need for more intensive services later in life (Jacobson, Mulick & Green, 1996) Appendix A.

  - ✔ In contrast, it is likely 90% of children who do not receive effective early intervention will require special or custodial care throughout their lives (FEAT, 1996).

- **Parents of children with ASD will be provided with materials and information specific to Autism Spectrum Disorders and evidence-based treatments/educational approaches at the beginning of the assessment process.**
  - ✔ Families must be able to choose from an array of scientifically supported options and need information to make informed decisions

- **Children with ASD will receive appropriate assessments and a diagnosis as soon as it is suspected.**

- **Support for children and their families in the home and community need to be family-centered. Families need information, training, emotional support, assistance accessing resources and support around advocacy for their child.**

- **Parents of children with ASD will be directly involved and included as participating partners in development of the Individual Family Support Plan (IFSP) and Individualized Education Plan (IEP).**

- **Nevada Regular and Special Education teachers as well as Related Service providers serving students with Autism Spectrum Disorders (ASD) must receive specialized training in best practices for children with these disorders. This training must include training and understanding of the core deficits of ASD. This training must lead to demonstrable competency in each of the following:**
    1. Program development including classroom-based approaches to communication and social development.
    2. Applied behavior analysis, including functional behavior assessment; educational and behavioral intervention through positive behavior support plans; staff management skills; and data collection.
    3. On-going training to keep core competencies current with evidence-based approaches.

- **Nevada childcare providers/daycare workers will be aware of the early signs of ASD and where to refer parents if concerns develop.**

Nevada children with Autism Spectrum Disorders deserve:

An effective therapy/treatment or instructional program which is or includes:

An intensive program involves carefully planned learning opportunities which are provided and reinforced at a high rate by trained therapists and teachers and is at least 25 hours per week, 12 months a year. Current research indicates that 30-40 hours per week provides optimal benefit.

- ✔ Based on current research and evidence-based practice;
- ✔ Based on comprehensive assessment results;
- ✔ Based on principles of applied behavior analysis;
- ✔ Determined by a multidisciplinary team that includes parents;
- ✔ Reflective of the individual's areas of need, addressing all domains including social skills, which drive the curriculum or service plan;
- ✔ Data-driven decision-making; Outcome based;
- ✔ Frequency of objectives being presented and hours of instruction must be included in the IFSP/IEP.
- ✔ Provided by appropriately trained and competent personnel, which should include parents as appropriate;
- ✔ Interventions for the reduction of problem behaviors should be based on the results of a functional assessment. Functional assessments must include direct observation or experimental (functional) analysis.
- ✔ Skill acquisition programs should involve positive consequences (rewards) for correct and appropriate responding. These consequences should be selected based on the results of a stimulus preference assessment.
- ✔ Assessment of a child's progress in meeting objectives should be used on an on-going basis to further refine the IFSP/IEP. Lack of objectively documented progress over a three month period should be taken to indicate a need to increase intensity by lowering student/teacher ratios, increasing programming time, reformulating curricula, or providing additional training and consultation.

- ✔ A child must receive sufficient individualized attention on a daily basis, so that individual objectives can be effectively implemented; individualized attention should include individual therapies, developmentally appropriate small group instruction, and direct one-to-one contact with teaching staff.

- ✔ Intensity of Instruction: An intensive program involves carefully planned learning opportunities which are provided and reinforced at a high rate by trained therapists and teachers (Bondy, 1996) and is at least 25 hours per week, 12 months a year (the National Research Council, 2001). Current research indicates that 30-40 hours per week provides optimal benefit (Anderson, Avery, Dipietro, Edwards & Christian, 1987, Lovaas & Smith, 1988, McEachin, Smith, & Lovaas, 1993, Sallows and Graupner, 2005) .

- ✔ When recommending hours of instruction consider the focus of the desired outcomes, the age and developmental level of the child, the needs of the family, the intensity and complexity of the child's needs, and the natural or least restrictive environment.

Best Practices for adults address following:

Issues:

Autism Spectrum Disorder (ASD) is often associated only with children, but it is a lifelong disability with no cure. Historically, the needs of those with ASD have been ignored as they grew beyond childhood, leaving adults abandoned by health and social services. Institutionalization was the rule with little hope offered to adults. They were kept behind locked doors in state hospitals, grouped with others with mental illness and mental retardation. Those with ASD were usually unidentified and were left untreated and underserved because of limited resources, inadequate staff, and lack of effective treatment methods.

"The price tag to care for one untreated low-functioning person with Autism to the age of 50 can run as high as $6 million."

Today we see a similar struggle for this population with limited resources and inadequate numbers of trained professionals to implement the services and treatment methods that could make a difference in these people's lives. However, there has been a change because this lack of care and services has now mostly become community-based, considering the limited options for institutional living and group homes.

Also, this move to community-based services has made it even more difficult to identify and even count the many adults who are living with ASD in the state of Nevada. While the school district attempts to report on childhood incidences in the state, there has not been a coordinated effort to identify adults with ASD. Attempts in other places have acknowledged the group is hard to measure, partly because so many people have grown up before improvements in recognition and diagnosis, which has left most labeled inappropriately as having mental health problems or learning difficulties.

The public schools' responsibility for providing services ends when the person with ASD reaches the age of 22. The family is then faced with the challenge of finding living arrangements and employment to match the particular needs of their adult child, as well as the programs and facilities that can provide support services to achieve these goals. Some adults with ASD, especially those with high-functioning autism or with Asperger syndrome, are able to work successfully in mainstream jobs. Many others with ASD are capable of employment in sheltered workshops under the supervision of managers trained in working with persons with disabilities.

Findings:

National statistics indicate only 12% of high functioning adults with ASD are employed (*Las Vegas Review Journal, 2007).*

Nevada needs to identify adults with ASD and ensure they are given the necessary supports and services that will enhance their independence and quality of life.

Supported group homes that can both liberate and shelter an adult with ASD are extremely rare, and a 10-year waiting list and costs of $75,000 a year, are typical. With an estimated 588 kids in Nevada with ASD (*Nevada Department of Education, Child Count, children ages 13+)* who will be adults soon, the commitment to make this possible for all of them will have to be huge.

The Nevada Provider Rates Task Force in 2002, stated the costs of long-term care in group homes or developmental centers will average $80,000 to $100,000 per year or in excess of $4 million over a lifetime past school age.

"The price tag to care for one untreated low-functioning person with Autism to the age of 50 can run as high as $6 million," stated James Mulick, PhD in his study of Pennsylvania costs associated with ASD. Appendix A

Conclusion:

A better understanding of the specific needs of people with ASD has opened the way for educational, social and vocational services that can address needs across the lifespan and make a real difference for adults. Nevada needs to identify adults with ASD and ensure they are given the necessary supports and services that will enhance their independence and quality of life.

Nevada adults with Autism Spectrum Disorders deserve services which are delivered using evidence-based practices:

Access to trained professionals who will teach and support job related skills.

- Supports and services for life-long care, with no regard given to the age when ASD was documented or the current age of the person. General supports and services would include psychological counseling, access to ASD resource center and ASD advocate, support group, special needs alliance organization, social service coordinator, personal care attendant, supports to obtain community inclusion, access to transportation, access to recreational support, respite care for adults still living with their families and access to educational support and post-secondary education support;

- Access to trained professionals who will provide evidence-based treatments specifically helpful for the adult population;

- Access to trained professionals who will teach and support job related skills. Work related supports and services would include communication skills training, computer & technology skills, job coach, supported employment, extra on the job training, co-worker support, assistive technology training, assessment for vocational transition, functional skills inventory to list and emphasis strengths, situational assessments with adaptations, modifications and restructuring examples, functional job resume written, vocational evaluations, integrated work opportunities, cross training, paid work experience;

- Access to trained professionals who will teach and support daily living skills. Independent living supports would include 24 hour crisis/helpline, assistance with self care, health and safety training, social /emotional/relationship skills training;

- Access to trained professionals to provide aid in securing appropriate housing. Help would include finding the best housing options among independent living and group living centers, adult day habilitation center, low-income housing, or 24-hour residential state facility;

- Access to trained professionals to provide aid with legal issues. Legal issues would include assistance with application process to obtain government benefits, assigned guardian or professional trustee, and inclusion in a state ID protection system;

- Access to medical and clinical services. Services would include ASD testing, health and life insurance, and routine medical and dental care;

- Access to financial services. A financial service provider or special needs alliance planer, would help with tax- free special needs trust, managing money and writing a specialized protective will.

Best Practices Supports Accuracy in Autism Prevalence

Issues:

In order to state true issues, Nevada needs accurate data. One of Nevada's downfalls is the lack of data that exist and also the improper analysis of data which does exit. School District data reports only children ages 3-21 with the single label of Autism Spectrum Disorders, lacking the capability to count those children with multiple labels. Nevada Early Interventions does not diagnosis on a consistent basis due to lack of resources, leaving their numbers suspect. Many of the children in the NEIS age group, children under 3 are not counted, as they are inappropriately labeled developmentally delayed. While other state agencies do not account for those who have not been diagnosised or who have not applied for services.

Formalized data collection on ASD prevalence would ensure efficient allocation of resources for early detection and intervention, and effective provision of necessary services to those with ASD and cost reductions.

Formalized data collection on ASD prevalence would ensure efficient allocation of resources for early detection and intervention, effective provision of necessary services to those with ASD and cost reductions.

Findings:

Using the CDC prevalence rate of 1 in 150 children , there should be an estimated 5,176 Nevadans ages 0-21 years old with ASD *(based on 776,333 age specific population, 2005*). 963 ages 0-3 yrs *(based on 144,517 age specific population, 2005*) 243 New Borns (based on 36,485 live births, 2005).

Nevada Early Intervention Services (NEIS) last reported numbers reflected only 150 children.

Nevada School Districts current count is 2,559 students with the single label of ASD.

A recent grant allowed UNR to start pulling data from agencies across the state. However without funding this program cannot continue.

The number of children identified with ASD in Nevada is only 50% of the expected number based on national prevalence rates of 1 in 150 (CDC, 2007).

Recommendations:

1. The Nevada Department of Health and Human Services and the Department of Education should collect data and report annually to the Governor and Legislative Counsel Bureau the numbers of Nevada children and adults who meet the criteria for ASD.

2. Fund a Nevada Autism Registry. An Autism Registry would collect a variety of data to answer questions, support future grant proposals and provide the state with accurate numbers of those affected by ASD.

3. Fund grants to improve current data collection systems to more accurately determine the number of Nevadans who meet the diagnostic criteria for ASD, independent of or in addition to other impairments.

Best Practices Supports Implementing Evidence-based Practices

Issue:

Nevada's delivery of service and treatment is inconsistent across state agencies and school districts. Evidence-based practices are often not supported and recognized, nor provided as the standard throughout Nevada. Often the staff who serve this population have little knowledge on the research surrounding treatments, and what makes a treatment evidence-based. Which results in inaccurate information or a lack of information relayed to the parent. Direct service providers need training to be competent to deliver intervention. Children are left waiting for a diagnosis and appropriate services. No cohesive integrated system has been developed in Nevada. Nevada, as a whole, has only begun to look at the problem and make recommendations through this document.

No cohesive integrated system has been developed in Nevada. Nevada, as a whole, has only begun to look at the problem and make recommendations through this document.

As more and more children are diagnosed or grow into adults without intervention the fiscal impact on the state and school districts resources will be affected. The importance of implementing the recommendations, delivering evidence-based treatments and collecting accurate data to understand the problem in its full scope is imperative.

Findings:

States such as California and New York have developed documents for Best Practices for Designing and Delivering Effective Programs for Individuals with ASD as a driving protocol or as a Guiding Principles document to facilitate consistency and uniformity across providers.

Other states support on-going Autism Task Forces, Autism Advisory Committees or Autism Centers of Excellence, some within their University systems. While other states provide grants to non-profits to provide oversight. An Advisory committee or Task Force is necessary to oversee implementation, information flow and training for continued consistency.

States such as New York and Maine have embraced Applied Behavior Analysis (ABA) as an evidence-based treatment and recognized its validity building programs to support its implementation.

Recommendations:

1. The Governor continue The Autism Task Force for an additional two years. Coordination and consistency are critical aspects of implementation planning. It is essential that Nevada develop a cohesive, integrated system for addressing

the recommendations delineated in this document. Such foresight will ensure excellence and efficiency in program development, and systematically reach every child, parent and provider.

2. The purpose of the Task Force will necessarily need to be modified to reflect a change of focus toward implementation planning. In light of this, additional appointments, sub-committees or consultants could be necessary such as an individual who can speak to transition, residency and employment, since the Task Force is addressing the lifespan.

3. The Autism Task Force should develop a Best Practices & Guiding Principles document, maintaing the intent of this document in regards to defining evidence-based treatments. Legislation needs to endorse and require said document to be utilized and followed by all state agencies, providers and schools districts with dissemination to parents.

4. The Legislature needs to require state agencies and school districts across the state to recognize and support evidence-based treatments.

5. The Legislature needs to require state agencies and school districts across the state to establish training and professional development to implement evidence-based treatments.

Best Practices Supports Evidence-Based Treatments at Recommended Intensity and the Funding to Provide Treatment Across the Lifespan

Issues:

Nevada does not require private insurance companies to cover even the essential autism treatments and services. In the absence of coverage, families often pay as much as they can out-of-pocket for services, which can cost upwards of $50,000 per year. In the process, many risk their homes and the educations of their unaffected children – essentially mortgaging their entire futures. Families are going broke as they struggle to provide their children with services they need and deserve. A family should not have to choose between getting necessary therapies for their child and making their mortgage payments. Children whose parents lack the financial means typically go untreated.

Costs can be reduced up to 2/3 with an early diagnosis and intense intervention.

State Medicaid does not cover Autism specific treatments.

Current state funding resources in place do not fund at the intensity level to meet recommendations. State funding allotments (O.D.S. and MHDS) are based on age rather than provider recommendations. Example: Ages 9 – 19 are funded at $778 per month, children 6-9 are funded at $1,037 per month and children 0-5 are funded at $1,555. per month. At the highest allotment, families can only purchase between 8 and 11 hours per week depending on which provider they use, which is far below what research recommends.

> An intensive program involves carefully planned learning opportunities which are provided and reinforced at a high rate by trained therapists and teachers (Bondy, 1996) and is at least 25 hours per week, 12 months a year. (the National Research Council, 2001) Current research indicates that 30-40 hours per week provides optimal benefit (Anderson, Avery, Dipietro, Edwards & Christian, 1987, Lovaas & Smith, 1988, McEachin, Smith, & Lovaas, 1993, Sallows and Graupner, 2005) .

The costs of lifetime care for an individual with ASD has been estimated at $3.2 million, (Harvard School of Public Health) 90% of which is incurred as adults. Costs can be reduced up to 2/3 with an early diagnosis and intense intervention.(J. Jacobson, J. Mulick, G. Green 1998). Research has demonstrated 47% of the children who receive an intense Applied Behavior Analysis, ABA program go on to live independent lives. (Appendex A - Cost-Benefit Impact)

As more and more children are diagnosed, the fiscal impact on the state and school

districts resources will be astronomical, if the state continues to ignore this problem. By improving outcomes for children with ASD, mandated private insurance coverage will decrease the lifetime costs of treating and providing services and will actually result in an overall cost savings in the long-run.

Findings:

Most insurance companies designate autism as a diagnostic exclusion, "meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition."

Lack of insurance coverage is a barrier to individuals with ASD receiving evidence-based treatments.

Government and scientific organizations have endorsed ABA and other structured behavioral therapies.

Without adequate insurance coverage the full burden falls on the state and school districts.

Lack of insurance coverage and adequate funding leads parents to try alternative treatments, which are not always evidence-based and at times even harmful.

Insurance coverage should support the needs across all ages. Insurance should provide coverage for evidence-based treatments at recommended intensity levels and medical coverage including diagnosis and evaluations.

Board Certified Behavior Analyst, BCBA prices range between $65 to $212 per hour in Nevada. Behavior interventionist (work under the supervision of a BCBA) rate of pay range from $10-$50 per hour based on experience and skill level.

Clark County School District, CCSD currently reimburses families at $10 and $12 per hour for behavior interventionists and pay between $1,000 - $1,500 per month for BCBA monthly consultation/program supervision. CCSD provides this additional funding to under a 100 children, while their numbers indicate they are educating over 1,900 children with the single label of Autism.

Sixteen states to date have provided insurance coverage for evidence-based treatments such as Applied Behavior Analysis (ABA) including our neighbor Arizona. The efficacy of ABA, the centerpiece of most of the states legislative mandate's benefits, has been established repeatedly.

Several studies have shown that as many as 47 percent of the children that undergo early intensive behavioral therapies achieve higher education placement and increased

IQ levels. A significant portion of children who receive ABA are placed into mainstream educational settings. Children who begin their treatment with minimal IQ levels end treatment with substantially higher levels of intellectual functioning. These results have been shown to last well beyond the end of treatment. As such, the effectiveness of ABA therapy has allowed many children to forego costly intensive special education in the future.[1]

Government and scientific organizations have endorsed ABA and other structured behavioral therapies. Its efficacy has been recognized in a number of prominent reports, including the following:

The 2001 U.S. Surgeon General's Report on Mental Health, which states, "Among the many methods available for treatment and education of people with Autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."[2]

The New York State Department of Health assessed interventions for children ages 0-3 with autism, and recommended that "behavioral intervention for reducing maladaptive behaviors be used for young children with autism for such behaviors interfere with the child's learning or socialization or present a hazard to the child or others."[3]

The Maine Administrators of Services for Children with Disabilities notes in their report that "There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include 'meaningful" outcomes such as increased social skills, communication skills, academic performance, and overall cognitive functioning. These reflect clinically-significant quality of life improvements. While studies varied as to the magnitudes of gains, all have demonstrated long term retention of gains made." [4]

The National Institute of Mental Health reports, "The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for an average 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones."[5]

The National Institute of Child Health and Human Development lists ABA among the recommended treatment methods for Autism Spectrum Disorders."[6]

The National Research Council's 2001 report on Educating Children with Autism acknowledged, "There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language, but also communication." [7]

Enact legislation to require health insurance coverage for evidence-based treatments and services for ASD across the life span at recommended intensity levels.

The Association for Science in Autism Treatment recommends ABA-based therapies, stating, "ABA is an effective intervention for many individuals with Autism Spectrum Disorders." [8]

Recommendations:

1. The Legislation must enact legislation to require health insurance coverage for evidence-based treatments and services for ASD across the life span at recommended intensity levels without ceiling caps. And Autism treatment yearly maximum not effecting medical provision. Mirroring Arizona legislation, with the exception on caps, if with caps $50,000 per year through age 9, and $25,000 per year through adulthood. Or Pennsylvania legislation, with a $36,000 per year cap, no age requirements. South Carolina is subject to a $50,000 maximum benefit per year up to age 16.

2. The Legislation must provide additional funding to the current state autism programs (O.D.S. and MHDS) at the intensity level supported by research, increasing funding levels to support provider recommendations based on the individual's needs or at a minimum 25 hours per week.

Best Practices Happen when Individuals with ASD Receive an Early Diagnosis, Appropriate Assessments and Evidence-based Treatment Prior to the Age of 3

Issue:

The majority of individuals with ASD are being diagnosed too late and not receiving the interventions needed; this is true for children of all ages, and is especially problematic for minority populations. The number of children identified with ASD in Nevada is only 50% of the expected number based on national prevalence rates of 1 in 150 (CDC, 2007).

Due to the lack of qualified professionals in Nevada and sometimes reluctance of providers to give a diagnosis, children continue to be undiagnosed.

Findings:

Currently the average age of diagnosis in the U.S. is between 4 and 5 years of age. National data on early identification indicates that most parents become concerned about their child's development between 15 and 18 months. Screening is possible at 18 months with the M-CHAT screening tool. Due to the lack of qualified professionals in Nevada and sometimes reluctance of providers to give a diagnosis, children continue to be undiagnosed.

According to, UNR, there are more children diagnosed whom, are parented by white educated parents. A fact, which indicates there are more barriers for minorities, culturally and liquistically diverse populations and members of lower socially economic status to access a diagnosis and treatment. According to the University of Nevada Center for Health Statistics and information, only seven percent of children receiving ASD services in Nevada are members of culturally and linquistically diverse populations. Nationally, the average age of diagnosis for a Hispanic child is six years old.

The importance of early diagnosis and treatment is well established amongst diverse groups of professionals *(Fenske, et al, 1985; Lovaas, 1987; Maurice, 1993; Perry, Cohen & DeCarlo, 1995)*. Researchers are finding "it may be the case that there is a "critical period" during which the young, developing brain is very modifiable. For some children with autism, the repeated, active interaction with the physical and social environment that is ensured by intensive behavior analytic treatment may modify their neural circuitry before it goes too much awry, correcting it before autism becomes become permanent *(Lovaas & Smith, 1989; Perry, Cohen & DeCarlo, 1995.)*

It is likely 90% of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives. (*Families for Early Autism Treatment (FEAT). "Doctor, My Child Doesn't Talk" The Importance of Early Autism Diagnosis." Video))*

Research indicates that early identification is associated with dramatically better outcomes for individuals with autism. The earlier a child is diagnosed, the earlier the child can begin benefiting from one of the many specialized intervention approaches to treatment and education *(Autism Society of America, 2008)*.

The American Academy of Pediatrics recommends that all children be screened for Autism by their family pediatrician twice by the age of 2, at 18 months and again at 24 months. The AAP also recommends that treatment be started when an autism diagnosis is suspected rather than waiting for a formal diagnosis. The advantages of early intervention cannot be overemphasized. Children who receive intensive therapy can make tremendous strides in their overall functioning and go on to lead productive lives.

The American Academy of Pediatrics recommends that all children be screened for Autism by their family pediatrician twice by the age of 2.

Recommendations:

1. The Nevada State Health Division should support an aggressive plan to encourage screening of every child for ASD as part of routine pediatric care.

2. The Nevada State Health Division should support developmental, behavioral and Autism-specific screenings for all Nevada children birth to age five years in collaboration with Nevada physicians and Early Intervention and Early Childhood Child Find programs. Results of these screenings should be tracked to determine the scope of ASD in Nevada.

3. The State of Nevada should seek additional federal funding and provide additional state funding to support increased early identification and intervention services for child at appropriate levels of intensity.

Best Practices Supports Quality Trained Professionals

Issues:

There is no consistent, state-wide standard of service and/or treatment in Nevada for children, youth and adults with ASD. That is, Nevada's state agencies and school districts do not regularly support, recognize or provide evidence-based services or education. Training is also inconsistant across the state and for paraprofessionals.

There is no consistent, state-wide standard of service and/ or treatment in Nevada for children, youth and adults with ASD.

Professional training and educational opportunities are severely limited in Nevada by the state's reluctance to fund UNR and UNLV's undergraduate and graduate programs in behavior analysis.

Individuals with ASD may exhibit behaviors which maybe interpreted as aggressive to untrained or uninformed first responders.

Findings:

Professional and paraprofessional staff employed by state agencies and school districts across Nevada need training on evidence-based practices. They must have a working, hands-on knowledge of evidence-based practices and must demonstrate specific competencies with respect to them.

Nevada Early Intervention Services support an eclectic approach that prominently excludes evidence-based practices.

There are limited training opportunities for first responders, law enforcement personnel and hospital staff who have contact with children, youth and adults with ASD.

There is no certification program for paraprofessionals working with individuals with ASD.

Clark County School District (CCSD) has adopted and is implementing Applied Behavior Analysis (ABA) for educating children and youth with ASD. Supplemental ABA services in the home and community are offered to some children. CCSD provides training for teachers, paraprofessionals and administrators. Washoe County School District (WCSD) has a small cadre of board certified behavior analysts who train and consult classroom teachers and paraprofessionals throughout the district. WCSD also has a small internship program involving graduate students in the behavior analysis program at UNR who assist in teacher and paraprofessional training and consultation. The state's other school districts have received limited or no training on the education and treatment of children and youth with ASD.

Recommendations:

1. Provide funding to the Nevada Department of Education for state-wide training grants on evidence-based practices for children, youth and adults with ASD in public school and in the community. These funds would be used to enhance existing programs in Reno and Las Vegas and to develop new programs in rural Nevada.
2. Provide funding to the Nevada State System of Higher Education to enhance the education and practical training of undergraduate and graduate students in behavior analysis at UNR and UNLV. Education and training for post-baccalaureate students should prepare them to sit for and pass the behavior analysis board certification examination at the associate level, and education and training for post-masters students should prepare them to sit for and pass the examination at the full, board certified level.
3. Provide state-wide funding for training to first responders, law enforcement personnel and hospital staff who contact children, youth and adults with ASD.

References

1. Major studies demonstrating effectiness of Applied Behavior Analysis for individuals with ASD:

Howard, J.S., Sparkman, C.R., Cohen, H.G., Green, G., Stanislaw, H. (2005). A comparision of intensive behavior analytic and elclectic treatments for young children with autism, *Research in Developmental Disabilities, 26, 359-83.*

29 children received Early Intensive Behavior Treatment, EIBT, 16 children attended a 30 hour per week special education program, and 16 children attended a 15-hour a week special education program. Children in the EIBT group demonstrated an average IQ increase of 31 points, while the children in the two special education programs demonstrated no statistically significant improvements in IQ scores. Despite receiving twice as many hours of intervention, the 30 hour per week special education group did no better than the 15 hour per week special education group on any measures of treatment outcomes.

Sallows, G.O. & Graupner, T.D. (2005), Intensive behavioral treatment for children with autism: four-year outcome and predictors, *American Journal on Mental Retardation, 110, 417-38.*

Sallows and his colleagues provided children with 31-38 hours per week of EIBT services. When assessed at age seven, 48% of these children demonstrated Iqs in the average range, and were attending regular education placements.

Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children, *Journal of Consulting and Clinical Psychology, 55, 3-9.*

A treatment group of children received an average of 40 hours per week of EIBT. 47% developed IQs in the average range and were able to attend regular education classes. While children receiving only 10 hours per week in the control did not achieve average IQs or go on to attend regular education classes.

McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral interventions, *American Journal of Mental Retardation, 97, 359-372.*

2. U.S. Department of Health and Human Services, Mental Health: *A Report of the Surgeon General, 163-164 (1999)*

3. New York Department of Health, Clinical Practice Guideline: Report of the Recommendations, Autism/ Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age0-3 years) (1999*)* Retreved from http://www.health.state.nv.us/community/infants_children/early_intervention/autism/index.htm

4. Maine Administrators of Services for Children with Disabilities, Report of the MADSEC Autism Task Force. (2000). Retrieved from http://www.madsec.org/docs/ATFReport.pdf

5. National Institute of Mental Health, Autism Spectrum Disorders, Pervasive Developmental Disorders. (2007) Retrieved from http://www.nimh.nih.gov/health/publications/autism/complete-publication.shtml

6. National Institute of Child Health and Human Development website: Questions and Answers (2006). Retrieved from http://www.nichd.nih.gov/publications/pubs/autism/QA/sub18.cfm

7. National Research Council, Educating Children with Autism. (Catherine Lord & james P. McGee eds 2001). Retrieved from http://www.nap.edu/openbook.php?isbn=0309072697

8. Association for Science in Autism Treatment website: http://www.asatonline.org/resources/resources.htm

John W. Jacobson, James A. Mulick, Gina Green, Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case. 13 *Behavioral Intervention, 201-26 (1998).*

APPENDIX A

Cost/Benefit

Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism General Model and Single State Case

John W. Jacobson, James A. Mulick and Gina Green

Click here to view Appendix A (pdf)

Education

Members of the Education Subcommittee

Korri Ward,
Chair
Parent, Rural Nevada
Nevada Autism Task Force Member

Melanie Stevens
Staff

Committee Members

Francis Allen
Nevada State Assemblywoman

Diane Branson
Nevada State Health Division Autism Training and Technical Assistance

Jan Crandy
Parent, Southern Nevada
Nevada Autism Task Force Member
Autism Coalition of Nevada, Southern Nevada Executive Director

Randy Figurski, MS CC-SLP
Manager
Nevada State Health Division Autism Training and Technical Assistance

Nicole Kalkowski
Parent, Southern Nevada

Carol Lambkin
Coordinator IV, Low Incidence Disability Team
Clark County School District

Cynthia McCray
Director, Low Incidence Disability Team
Clark County School District

James Ohrenschall
Nevada State Assemblyman

Cathy Scott
Southwest Region Director, Student Support Services Division
Clark County School District

Jennifer Van Tress
Assistant Principal, Moss ES & Caughlin Ranch ES
Washoe County School District

Thank you to Special Guest:
Susan Lawrence
Director of Special Services
Elko County School District

Education

Executive Summary

There are no widely accepted or implemented educational guidelines that establish quality of service for ASD and there are significant gaps in knowledge about ASD amongst agency staff, school staff, administrators, and families.

Individuals with Autism Spectrum Disorders require a comprehensive range of educational services. The service requirements of individuals and families with ASD are intense and require a long-term approach to address chronic needs. The number of individuals with Autism Spectrum Disorders continues to increase and Nevada schools and agencies are struggling to meet the educational needs of this population. Though Nevada has effective programs, they tend to be scattered and insufficient to meet the needs of individuals throughout the state. It is critical that professionals that serve children and adults with Autism Spectrum Disorders in Nevada demonstrate competency in implementing applied behavior analysis principles. There are no widely accepted or implemented educational guidelines that establish quality of service for ASD and there are significant gaps in knowledge about ASD amongst agency staff, school staff, administrators, and families. The increased incidence of ASD has greatly increased the demands on the educational system due to the complexity of ASD, including the unique ways individuals with ASD process and respond to information, the variability of how ASD affects each child, and the often extreme and unusual communication and socialization challenges of children with ASD. Nevada must respond by enhancing existing systems and expanding services to children and adults with ASD and their families.

I. Teachers

Issues

Teachers report that case loads/ class sizes are too high to effectively meet the needs of the students with Autism Spectrum Disorders.

- There are high teacher shortages in Autism.
- Staff retention in classrooms serving students with Autism is problematic.
- Providing sufficient in-services and follow-up training for staff is difficult.
- Difficulty finding trained staff for early intervention, birth to 3 years of age and adult agencies.
- Difficulty in retaining staff in agencies serving birth to three and adult populations.

Findings

- Shortage of teachers with Autism endorsements
- Teachers report being overburdened by paperwork, especially high with students who have Autism Spectrum Disorders.
- Rural schools have difficulty providing specific training for teachers and paraprofessionals who serve students with Autism Spectrum Disorders.
- Teachers report that case loads/class sizes are too high to effectively meet the needs of the students with Autism Spectrum Disorders.
- Speech/Language Pathologists report being overburdened to meet the paperwork demands and intensity of services for students with Autism Spectrum Disorders.
- Occupational Therapists do not have a case load cap. This puts an undue burden on them when serving students with Autism Spectrum Disorders.
- Some school personnel do not utilize positive behavior supports in general education settings
- Individuals with Autism Spectrum Disorders are served in a variety of school settings: general education classrooms, resource rooms, and self-contained classrooms
- Paraprofessionals need additional training to support students with Autism Spectrum Disorders.
- Clark County School District provides in-services for staff who work with students identified under the Autism eligibility. The trainings are a two day lecture that covers the characteristics of autism, Applied Behavior Analysis, and Discrete Trial Training. Additional trainings are: a 4 day hand-on, paraprofessional training-one day at a central site and one where the paraprofessional works, a ½ day curriculum training, and a ½ day social skills training.
- Clark County School District offers technical assistance support, through consultation and classroom site visits.

Recommendations

1. Offer school districts incentives to develop tiered professional development for licensed staff and support staff to get additional training specific in Autism Spectrum Disorders.

2. State support two day lecture on autism-background on Autism Spectrum Disorders and Discrete Trial Teaching techniques

3. State support Hands-on training for Discrete Trial Teaching

4. State support autism training teams (6 teams for Clark County School District, 2 teams for Washoe School District, 1 team for Carson City School District, and a state team to support rural districts).

Advise the Professional Standards Board to allow Alternative Route to Licensure five (5) years to complete the generalist license and Autism endorsement.

5. State Department of Education support online training for teachers and paraprofessionals working with students who have Autism Spectrum Disorders.

6. State Department of Education support colleges to offer online or distance education college courses that meet the endorsement requirements for teachers

7. State Department of Education support training positive behavior supports in the rural districts

8. Lower case loads for Speech/Language Therapists who support students with Autism Spectrum Disorders to 30

9. Provide funding to streamline data collection that is user-friendly.

10. Legislation that supports school districts being able to develop a mentoring system to support staff serving individuals with Autism Spectrum Disorders.

11. Legislation to fund teachers earning their special education license and endorsement in Autism.

12. Advise the Professional Standards Board to allow Alternative Route to Licensure five (5) years to complete the generalist license and Autism endorsement.

13. State Department of Education assist with identifying a case load cap of 30 for Occupational Therapists working in school districts.

14. Pilot lower case load and class size so teachers can meet the paperwork demands-students with are in every program (general education, resource classes, and self-contained classrooms)

	Type of Program	Class Size/Case Load	w/Assistant
o	Resource	10/12	12
	SELF-CONTAINED		
o	Autism	4/6	6
o	ECSE/Specialized	8/10	10
o	Learning Disabilities	10/12	12
o	Moderately MR	8/10	10
o	Severe MR	4/6	6

Pilot lower case load and class size so teachers can meet the paperwork demands- students with are in every program (general education, resource classes, and self-contained classrooms)

15. Pilot changes to NAC and state IEP that identifies level of need rather than location. NOTE: similar to reporting to the federal government about percentage of time in general education rather than naming a location.
    - type of service needed, consult or direct
        - push in to general education classroom
        - pull out to a intensive intervention setting, no more than 6 students with disabilities or with an assistant from 7-10 students with disabilities
    - where support will be provided (push-in to general education classroom, pull-out classroom in another room, pull-out classroom at another comprehensive campus, pull-out classroom at a special school)
        - Class Sizes
            - General education classroom, same as NAC
            - Pull-out classroom at no more than 10 students with a special education teacher and an assistant

II. Paraprofessionals

Issues:

The state of Nevada does not require specific training or a certification for paraprofessionals who work with individuals with Autism Spectrum Disorders. Rate of pay is not based on meeting any core competencies, nor is knowledge and advanced skills rewarded by a higher salary. Turn over is high among both teachers and paraprofessionals who serve the Autism population.

One of the reasons cited by teachers for not remaining in an ASD classroom is the lack of support from a trained paraprofessional.

Children with ASD often demonstrate behaviors on a daily basis, making their needs intense for the teaching staff. Without trained support in a classroom, teachers often spend their day redirecting the higher needs child, while providing less instructional time for the other students in the class. It is not unusual for a class to consist of 8 children with ASD and a ratio of one teacher and one paraprofessional. One of the reasons cited by teachers for not remaining in an ASD classroom is the lack of support from a trained paraprofessional.

"The paraprofessional plays a key role in any program for students with autism. Paraprofessionals may be used within a self-contained program, or may be hired as a one-on-one assistant in a general education classroom. Given the breadth of responsibilities of a paraprofessional, they are under immense pressure to perform in a variety of settings and with many different teachers. Although the school district may provide some general training in first aid and student confidentiality, many paraprofessionals have little or no experience or specialized training in working with students with autism."[1]

"One of the potential resources for providing special services for children with Autism Spectrum Disorders is the paraprofessional. Given the personnel shortages, that seems likely to continue into the future, some attempt to include para-educators within educational intervention programs for children with autism seems highly desirable."[2]

"Paraprofessionals identified their most important training need as knowledge of specific disabilities."[3]

"Practitioners, families and researchers alike express concern that the current use of paraprofessionals means the least qualified personnel provide the majority of instruction and support to the students with the most significant needs and challenges." [4]

The quality of support that paraprofessionals are able to provide students depends on the initiative and financial resources of individual school districts. As with teachers,

paraprofessionals must receive training if they are to be effective. This training needs to be more than the occasional workshop. Training should be ongoing and hands on.

Paraprofessionals provide support to students in self-contained classrooms and in the general education environment. Both types of support require a different level of skill sets. Paraprofessionals lacking knowledge of ASD and how to properly support them have a greater potential of creating prompt dependent students.

County School District (CCSD) has adopted and is implementing Applied Behavior Analysis (ABA) for educating children and youth with ASD.

Paraprofessionals are instrumental to the success of individuals with ASD as well as providing the necessary support to teachers. Given knowledge of ASD and appropriate training, paraprofessionals become part of a classroom team which, can better support students and become a key role in their success. Success means helping the student become independent. Critical areas of knowledge also include having the skill level to know when to provide support and than knowing how to fade prompts.

Social skills are a major deficit for individuals with ASD. A trained paraprofessional plays a key role in supporting students in navigating peer relationships within the school environment.

"The general education setting is considered to be a fertile ground for the development of peer interactions and relationships. These peer interactions have been empirically linked to increase achievement and self esteem." [5]

Development of a paraprofessional certification would require competencies, which would provide the framework for consistent statewide standards by which paraprofessional training and professional development can be created and evaluated at the state, district and school levels.

Findings:

Nevada paraprofessionals currently working in the classroom with children with Autism Spectrum Disorders (ASD) receive limited or no training in the area of ASD. Clark County School District (CCSD) has adopted and is implementing Applied Behavior Analysis (ABA) for educating children and youth with ASD. CCSD provides training for teachers, paraprofessionals and administrators. Washoe County School District (WCSD) has a small cadre of board certified behavior analysts who train and consult to classroom teachers and paraprofessionals throughout the district. WCSD also has a small internship program involving graduate students in the behavior analysis program at UNR who assist in teacher and paraprofessional training and consultation. The state's other school districts have received limited or no training on the education and treatment of children and youth with ASD.

Nevada School Districts report difficulty in retaining teachers and paraprofessionals. A higher salary level may decrease the shifting of paraprofessional's assignments.

Training and implementation of autism specific programs are inconsistent across districts and schools.

Development of a paraprofessional certification would require competencies, which would provide the framework for consistent statewide standards by which paraprofessional training and professional development can be created and evaluated at the state, district and school levels.

Paraprofessionals in Nevada are required to have a high school diploma except those working at a Title I schools where there are additional requirements. Title I paraprofessionals requirements include 60 credits Associate degree or passing a high stakes tests.

"IDEA requires that paraprofessionals be "appropriately trained and supervised, in accordance with state law, regulation or written policy."[6]

Other states such as Minnesota, Virginia, and California have addressed the issues of appropriate training for staff and have developed core competencies and/or certification processes which reflect pay scales based on meeting stated criteria.
(Appendixes B, C, D)

West Virginia established in 1992 the autism mentor credential for qualified paraprofessionals. The credential requires at least 30 hours in autism-related staff development credit and two years of work with students with ASD in addition to meeting higher level paraprofessional requirements (Aide III). The credential also raises them to a higher salary level.

Recommendations:

1. Require the Nevada Department of Education, in collaboration with School Districts and the Autism Task Force to develop competencies to guide paraprofessional development based on evidence-based practices and the most current research. Competencies would include knowledge and demonstration in practice. Meeting competencies would begin after entry-level.

   Revise the NAC's definition of "appropriately trained" paraprofessionals to include the finalized competencies.

2. Provide funding to the Nevada Department of Education for statewide training grants for paraprofessionals on evidence-based practices for individuals with ASD in public school.

3. Provide funding to the Nevada University and Community College systems to create a certification program for paraprofessionals.

4. Legislation to provide funding to school districts for paraprofessionals as a separate funded position.
5. Develop and set paraprofessional salary levels, based on a tier system of meeting defined competencies.

III. Parents

Issues:

Parenting a child with autism is demanding on a family's resources, time and patience. Typical parenting books do not give parents the skills they need to reduce their child's inappropriate behaviors or to teach their child daily living skills. Not having a central location for autism related information increases the parents' stress, as they try to cope with very a difficult and uncertain day to day life. Parents oftentimes get conflicting information about their child's disability. Parents are faced with many challenges while learning about the disability including finding reputable resources to access and who is responsible for providing information. Effectively parenting a child with autism requires continuous implementation of behavior strategies, communication techniques, and specialized teaching techniques in the home and community. Families should be provided the opportunity to learn child specific evidenced-based techniques to teach skills and to reduce their child's inappropriate behaviors.

It is well established that parents can learn and successfully apply skills to changing the behavior of their children with Autism Spectrum Disorders.

Findings:

"It is well established that parents can learn and successfully apply skills to changing the behavior of their children with Autism Spectrum Disorders"[7]

IDEA 2004 34 C.F.R. § 300.24 defines related services as including parent counseling and training.

NAC 388.101 supports the definition of related services in 34 C.F.R. § 300.24 to include parent counseling and training.

In the Olmstead decision (1999), the Supreme Court required States to place qualified individuals with mental disabilities in community settings, rather than in institutions. In compliance with the Olmstead decision Nevada is moving people from the institutional setting to a community setting. Parents of children with autism in Nevada are faced with the tremendous challenge of caring for severely disabled individuals within their home with limited supports and oftentimes no training.

Lovaas demonstrated that children whose parents were trained to continue therapy continued to improve, while children who were institutionalized regressed.[8]

In Nevada, children with Autism live at home.[9]

Clark County School District trained 77 families (July 2007- May 2008) and 113 families (July 2006 - June 2007) at the Connection Center. The training is five two

hour sessions that teach parents how to deal with difficult behaviors using ABA. The staff follows-up at the home for three or more generalization sessions. Other districts do not have a parent training center.

Recommendations:

1. Fund Autism Coalition of Nevada, ACON, to enhance and maintain their web-site, which identifies services, providers, and support groups throughout Nevada.
2. Provide regional autism centers, which parents can go into to get general autism information, assistance, best practices, research information about treatments, and referrals to programs. Fund grant process to work within existing university and community college systems to develop regional autism centers to provide ongoing community based assistance to families in Southern Nevada, Northwest Nevada and rural Nevada.
3. Fund child specific parent education through the Connection Center in Southern Nevada and a similar center in Northwest Nevada.. The rural areas would better be served by funding a State Autism Team to provide similar services as the Connection Centers in urban areas.

References

[1] L. Ernsperger, Ph.D, formally of Clark County School District, (2003). *Keys to Success for Teaching Students with Autism,* 143

[2] National Research Council (2001). *Educating Children with Autism.* Committee on Educational Interventions for Children with Autism. Catherine Lord and James P. McGee, eds. Division of Behavioral Social Scineces and Education. Washington, DC; National Academy Press

[3] (Riggs, 2001)

[4] (Brown, Farrington, Knight, Ross & Ziegler, 1999; Giangreco et al, 2001)

[5] (Johnson & Johnson 1985, Kirova, 2001; Nave,1990).

[6] (NCLB, 2002)

[7] National Research Council (2001). *Educating Children with Autism.* Committee on Educational Interventions for Children with Autism. Catherine Lord and James P. McGee, eds. Division of Behavioral Social Scineces and Education. Washington, DC; National Academy Press, 215

8 Lovaas, O.I., Koegel, R.,Simmons, J.Q., & Long, L.S., (1973) Some Generalizations and Follow-up Measures on Autistic Children in Behavior Therapy. *Journal of Applied Behiavor Analysis, 6,* 131-165

[9] 27th Annual Report to Congress on the Implementation of the *Individuals with Disabilities Education Act*, 2005, Vol. 2, http://www.ed.gov/about/reports/annual/osep/2005/parts-b-c/27th-vol-2.pdf)

APPENDIX B

Minnesota Paraprofessional

Click here to view Appendix B (pdf)

APPENDIX C

San Jose Paraprofessional
Autism Spectrum Disorders Specialized Competencies

Click here to view Appendix C (pdf)

APPENDIX D

Competencies for Professionals and Paraprofessionals Supporting Individuals with Autism Across the Lifespan in Virginia

Click here to view Appendix D (pdf)

Please click on Appendix D within the pdf folder to review this document.

Financing Comprehensive Systems of Care

Members of the Finance Subcommittee

Todd Butterworth, Chair
Bureau Chief
Nevada Office of Disability Services

Melanie Stevens
Staff

Committee Members

Roswell Allen
Sierra Regional Center

Connie Anderson
Nevada Medicaid

Catherine Armstrong
Nevada Early Intervention Services

Amy Clemens
Financial Advisor
Waddell & Reed

Randy Figurski, MS CC-SLP

Mary Liveratti
Deputy Director
Department of Health and Human Services

James Ohrenschall
Nevada State Assemblyman

Daine Ross
The Continuum

Shawna Ross
Sierra Speech

Nancy Sylvanie, Ph.D.

Korri Ward
Parent, Rural Nevada
Nevada Autism Task Force Member

Financing Comprehensive Systems of Care

Executive Summary

Insurance reform will help spread the high cost of Autism treatment across the community.

Other sections of this report outline important philosophies, strategies, values and outcomes associated with proactively addressing the needs of Nevadans with Autism. This section addresses the means to those ends, placing an emphasis on balancing public, private and personal investment in treating Autism Spectrum Disorders; maximizing the impact of every dollar invested; and vesting those who are most affected, and who have the most situational knowledge, with influence in spending decisions.

In particular, this section looks at how insurance reform will help spread the high cost of Autism treatment across the community; how more open competition among service providers will attract more providers and keep prices reasonable; and how the State can make a difference by expanding what it already does, rather than developing new programs.

Summary of Issues and Findings

Insurance- Issues

1. Many families living with Autism who participate in health insurance programs are shocked to discover that Autism and related disorders are specifically excluded from their policy's schedule of benefits.

2. By prohibiting coverage of treatment needed by Nevada's policyholders with Autism, insurance companies are effectively passing these costs on to State programs, including Early Intervention Services, K-12 Education, Medicaid, Mental Health and Developmental Services, Independent Living Services and Vocational Rehabilitation. Combined, these programs spend millions of dollars each year providing services that insurance companies refuse to cover.

By prohibiting coverage of treatment needed by Nevada's policyholders with Autism, insurance companies are effectively passing these costs on to State programs, including Early Intervention Services, K-12 Education, Medicaid, Mental Health and Developmental Services, Independent Living Services and Vocational Rehabilitation.

3. Some families living with Autism receive health benefits under a risk management method referred to as "self insurance." While self insurance is common in Nevada, treatments for Autism are universally excluded under Nevada's existing self insurance programs. (Self insurance is a risk management method whereby a risk is retained, but a calculated amount of money is set aside to compensate for the potential future loss.)

Insurance- Findings

1. The US government's military health insurance system, TriCare, now offers coverage for vital Autism services, including evidence-based behavioral interventions.

2. As of 2007, there were 17 states with statutory provisions related to insurance coverage for Autism.

3. Of those states, ten require coverage for Autism under provisions for mental health coverage, and six have separate provisions specifically related to Autism. Here is a brief overview of the insurance statutes that specifically address Autism:

Arizona Coverage for Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorders "not otherwise specified" (PDD-NOS). Policies cannot exclude or deny coverage for a treatment or impose dollar limits, deductibles and coinsurance provisions based solely on the diagnosis of Autism Spectrum Disorder. Treatment includes diagnosis, assessment and services. Reguires coverage for services provided outside of state. Behavioral therapy is consider medically necessary. *"Behavioral therapy" means interactive therapies derived from evidence based research, including Applied Behavioral Analysis, which includes discrete trial training, pivotal response training, intensive intervention programs and early intensive behavioral intervention.* To be eligible for coverage, behavioral therapy services shall be provided or supervised by a licensed or certified provider. Coverage for behavioral therapy is subject to a fifty thousand dollar maximum benefit per year for an eligible person up to the age of nine; a twenty-five thousand dollar maximum benefit per year for an eligible person who is between the ages of nine and sixteen. (Az. Code A.R.S. § 20-826.04).

Georgia If an insurance policy includes benefits for neurological disorders, it is prohibited from denying benefits for Autism. Such benefits are subject to the same terms and conditions as those for neurological disorders (Ga. Code Ann. § 33-24-59. 10).

Indiana Policies must include coverage for pervasive developmental disorders, including Autism. Coverage may not be subject to dollar limits, deductibles, co-payments, or coinsurance provisions that are less favorable to an insured than those that apply to a physical illness. Insurers and HMOs cannot deny or refuse to issue coverage on, refuse to contract with, refuse to renew or reissue, or otherwise terminate or restrict coverage on an individual because of a pervasive developmental disorder diagnosis (Ind. Code §§ 27-13-7-14. 7 and 27-8-14. 2-1 through 27-8-14. 2-5).

Maryland Policies must include coverage for habilitative services for children under age 19. "Habilitative services" means services, including occupational, physical, and speech therapies, for the treatment of a child with a congenital or genetic birth defect, including Autism, to enhance the child's ability to function. Reimbursement for habilitative services delivered through early intervention or school services is not required (Md. Code Ann. § 15-835).

New York Policies are prohibited from excluding coverage for the diagnosis and treatment of Autism Spectrum Disorders (ASD), including Autism (NY Ins. Law § 3221(l)(17), effective January 1, 2007).

Pennsylvania Requires health insurance policies and the medical assistance program to cover the diagnosis of ASD and treatment of ASD under twenty-one years of age. ASD specific coverage subject to thirty-six thousand dollars per year, but no lifetime benefit caps or visit limits. Coverage includes Pharmacy care, Psychiatric care, Psychological care, Therapeutic care including speech, occupational and physical therapies, Rehabilitative care, including applied behavior analysis, which are necessary to develop, maintain and restore to the maximum extent practicable, the functioning of an individual.The maximum yearly benefit cap will be adjusted for inflation. after 12/30/2011. (Pennsylvania HB 1150 passed 2008). Appendix F

South Carolina Coverage Includes: Treatments, including behavioral therapies, which are prescribed by the individual's treating medical doctor in accordance with a treatment plan. Age Range: An individual must be diagnosed with Autistic Spectrum Disorder at age eight or younger. The coverage must be provided to any eligible person less than sixteen years of age. Dollar Cap: Coverage for behavioral therapy is subject to a $50,000 maximum benefit per year. (Public Act 08-132 July, 2008)

Tennessee If a policy includes benefits for neurological disorders, it must provide benefits for ASD to children under age 12. Such benefits must be at least as comprehensive as those provided for other neurological disorders (Tenn. Code. Ann. § 56-7-2367).

4. Two states have addressed Autism coverage under self-insurance programs; Here is a brief overview of their statutes:

Wisconsin Requires health insurance policies and governmental and school district self-insured health plans to cover the cost of treatment for Autism, Asperger's Syndrome, and pervasive developmental disorders not otherwise specified. The treatment must be provided by a psychiatrist, psychologist, a social worker who is certified or licensed to practice psychotherapy, a paraprofessional working under the supervision of any of those three types of providers, or a professional working under the supervision of an outpatient mental health clinic.

The coverage requirement applies to: both individual and group health insurance policies and plans, including defined network plans and cooperative sickness care associations; to health care plans offered by the state to its employees, including a self-insured plan; and to self-insured health plans of counties, cities, towns, villages, and school districts. The requirement specifically does

not apply to limited-scope benefit plans, Medicare replacement or supplement policies, long-term care policies, or policies covering only certain specified diseases. The coverage may be subject to any limitations or exclusions or cost-sharing provisions that apply generally under the policy or plan. (WI Senate Bill 178 and Assembly Substitute Amendment 1 to Senate Bill 178)

The Nevada Legislature is asked to ensure that Autism Spectrum Disorder is treated as any other medical condition, by passing insurance legislation that will require health insurance policies to cover the screening, diagnosis and treatment of Autism Spectrum Disorders

Illinois If a county is a self-insurer for purposes of providing health insurance coverage for its employees, the coverage shall include coverage for…Autism up to annual limits of $36,000 but without limits as to the number of visits to an Autism service provider. Benefits for other conditions not related to Autism by an individual affected by ASD may not be applied to the maximum $36,000 ASD benefit… subject to the same deductibles, co-payments and coinsurance provisions in the health insurance policy. Treatment for Autism Spectrum Disorders shall include: psychiatric care, psychological care, rehabilitative care, therapeutic care including speech, occupational, and physical therapy, pharmacy care, applied behavior analysis therapy, and any care, treatment, intervention, service or item for individuals with an Autism Spectrum Disorder which is determined by the Department of Health Care and Family Services, based upon its review of best practices or evidenced-based research, to be medically necessary.

Insurance- Recommendations From Executive Summary

1. The Nevada Legislature is asked to ensure that Autism Spectrum Disorder is treated as any other medical condition, by passing insurance legislation that will:
    a. In general, require health insurance policies and the medical assistance program to cover the screening, diagnosis and treatment of Autism Spectrum Disorders in individuals less than 21 years of age. Applies to policies offered, issued, or renewed on or after July 1, 2009, to groups of 51 or more employees. Include all insurance programs in Nevada, including self-funded and self-insured plans.
    b. Benefit limits – Coverage for evidence-based behavioral therapies are subject to a maximum yearly benefit of $36,000 but no lifetime benefit caps or visit limits. After December 30, 2011, the maximum yearly benefit will be adjusted for inflation.
    Coverage is subject to co-payment, deductible, coinsurance provisions, and general policy or program limitations and exclusions to the same extent as other medical services.
    c. Authorized treatment – The treatment of Autism Spectrum Disorders includes the following medically necessary care identified in a treatment

plan:

i. Prescribed medications and any test needed to determine their effectiveness;
ii. Psychiatric care;
iii. Psychological care;
iv. Habilitative and rehabilitative care, including Applied Behavior Analysis (ABA);
and
v. Speech therapy, occupational therapy, and physical therapy.
vi. Allow for a Physician or Psychologist or qualified Masters-level professional to develop the treatment plan for autism spectrum disorder. An insurer may review the treatment plan once every six months, unless the insurer and physician or psychologist agree that more or less frequent review is necessary.
vii. As a cost savings measure, allow reimbursement of Masters-level, licensed therapeutic care professionals, as well as paraprofessional therapists when working under the supervision of a Masters-level (or greater), licensed professional.
viii. Providers – The Nevada Psychology Board, in consultation with other appropriate state agencies, will set standards for behavior specialists, a newly recognized group of service providers.

Insurance- Recommendations

1. The Nevada Legislature is encouraged to pass legislation requiring insurance coverage for Autism services. This legislation should:

    a. Include all insurance programs in Nevada, including self-funded and self-insured plans.

    b. Disallow pre-existing condition exclusions.

    c. Specify that coverage may not be subject to dollar limits, deductibles, co-payments, or coinsurance provisions that are less favorable to an insured with Autism than those that apply to a physical illness.

    d. Specify that benefits must be at least as comprehensive as those provided for other neurological disorders under the policy, if applicable.

    e. Require coverage for coordination time among members of the treatment team.

    f. Empower the treating physician to direct the plan of care.

    g. Ensure that insurance coverage cannot be denied based upon services being available through a public program.

Pass legislation requiring insurance coverage for Autism treatments to include: Prescribed medications and any test needed to determine their effectiveness; Psychiatric care; Psychological care; Habilitative and rehabilitative care, including Applied Behavior Analysis (ABA); and Speech therapy, occupational therapy, and physical therapy.

h. As a cost savings measure, allow reimbursement of Masters-level, licensed therapeutic care professionals, as well as paraprofessional therapists when working under the supervision of a Masters-level (or greater), licensed professional.

i. Allow plan of care reviews no more often than every six months, and require that reviewers have demonstrated expertise in Autism treatment.

j. If benefits are capped, the cap must be appropriate and reasonable and the cost of heath services not related to Autism should not count against that cap.

k. Coverage must include Applied Behavioral Analysis.

Any Willing Provider- Issues

1. When Nevada passes legislation mandating insurance coverage for individuals with Autism Spectrum Disorders, families in some insurance plans will still face other barriers. These barriers may include not being able to find an in-network provider (especially in rural areas) or having to schedule services during school hours even though there are other highly qualified professionals in the area with after-school appointment times available.
2. A typical Any Willing Provider (AWP) law requires all health insurers to be ready and willing at all times to enter into service contracts with all health care providers who are qualified under state law, who practice within the general geographic area served by the insurance company, and who are willing to meet the terms and the conditions set forth by the insurer.
3. An AWP law enables market forces, rather than arbitrary decisions, to determine the equilibrium point for the supply and demand of particular medical services.

Any Willing Provider- Findings

1. Seven states have Any Willing Provider (AWP) laws that apply broadly to medical providers. There are additional states that have AWP laws that pertain specifically to pharmacies.
2. Opponents of the concept claim it undermines cost control mechanisms employed by health plans which allow them to offer lower premiums to enrollees; insurance companies also argue that they then cannot contract with the most highly qualified providers and they incur increased operating costs.

a. The universal application used in Nevada to initiate a contract with an insurance company does not include any clinical information, does not ask for samples of treatment plans or other therapy-specific information, and includes only administrative information (such as state license number, tax ID number, malpractice insurance information, etc); it does ask for a resume and a list of references but anecdotal evidence reveals that these are seldom used.

b. Medical professionals report, when being denied access to an insurance plan in Northern Nevada, that the insurance company stated that there are currently enough providers in the area to serve their policyholders, despite the fact that after-school appointments are hard to come by. The insurance company advised that, until all plan providers reach 100% patient capacity, no more providers will be added to the panel. This approach seems to undermine the competitive forces that would benefit both the insurance company and the insured.

3. Proponents of AWP argue that, by selectively contracting and thereby excluding some providers, health plans are threatening providers' freedom to practice. Because providers increasingly depend on managed health plans as a source of income, they have lobbied aggressively for laws that would obligate plans to contract with any provider who meets the terms of participation.

Any Willing Provider- Recommendations

1. The Nevada Legislature is encouraged to pass an Any Willing Provider law, which:

   a. Is not specific to pharmacists and which includes all service providers who serve individuals with Autism.

   b. Is broad in scope, applying to all or most licensed providers in the state.

   c. Details a list of specialties covered by the statute or asserts that the provisions apply to all specialties licensed in the state without specifically listing any.

   d. Includes a provision that reimbursement rates to such providers be consistent with similar providers already contracted with that insurance company.

   e. Specifies that provider enrollment is always open and not constrained to time limits or to certain times of the year.

Medicaid - Issues

1. Currently, Nevada Medicaid and Nevada Check Up do not offer Applied Behavioral Analysis (ABA) or similar services traditionally needed by individuals with Autism. Adding these services to the Medicaid State Plan would require offering them to everyone on Medicaid, who would qualify for this service. Providing this benefit could be an expensive proposition.

Currently, Nevada Medicaid and Nevada Check Up do not offer Applied Behavioral Analysis (ABA) or similar services traditionally needed by individuals with Autism.

2. Services like ABA can only be targeted to a specific population (such as people with Autism) through a Medicaid Waiver. A Waiver enables the State to obtain federal Medicaid matching funds for medically necessary services.

3. However, there are three major drawbacks to a Waiver:

    a. First, Waiver applicants must be lower-income (normally a special income level of 300% of SSI). This means that a waiver would exclude most families on income criteria alone.

    b. Second, participants in home and community-based Waivers must meet nursing facility or ICF/MR level of care criteria and be at risk of institutionalization. Most children with Autism will not meet these requirements.

    c. Third, a Waiver must be cost-neutral, meaning that the cost to serve an average client on the Waiver must be less than or equal to the cost of institutional care. Because of the intense services needed for someone with severe Autism, an Autism Waiver may struggle to achieve cost-neutrality.

Data from the Office of Disability Services Autism program indicate that less than 10% of their applicants would meet both criteria A and B above.

Medicaid - Findings

1. At least four states offer Autism services through a Medicaid Waiver; these states include Wisconsin, Indiana, Colorado and Maryland.

2. Some states have implemented a stand-alone Waiver for Autism and others have incorporated Autism services under existing Waivers.

3. IQ measurements, which are often used in Waiver programs for other mental disabilities, don't work well for Autism because of the broad range of IQs found among people with Autism. Functional criteria offer a better measurement for Autism care needs.

4. The administration of Autism Medicaid Waivers sometimes fits better outside the Mental Health or Developmental Disabilities service system.

Medicaid - Recommendations

1. Given the investment of State resources necessary to develop an Autism Waiver, the limited number of Nevadans who could likely be served by such a Waiver, and the anticipated difficulty in getting a new Waiver approved by the Centers for Medicare and Medicaid services, it is recommended that Nevada instead increase its investment in the existing Autism service programs through the MHDS Regional Centers and the Office of Disability Services. This recommendation may change as the factors listed here evolve.

2. The absence of a Waiver should also be offset by an increased appropriation to Vocational Rehabilitation (which offers a 4 to 1 federal match) to build transitional supports for young adults with Autism moving from high school into adult training, education and work.

3. Consider adding Applied Behavior Analysisi, (ABA) under Medicaid State Plan services and Nevada Check Up.

There are scant federal resources dedicated to Autism intervention. As a result, kids who might have had their Autism mitigated through early treatment, and who might have gone on to lead productive lives, instead continue to be dependent as adults and often turn to State programs—like Welfare, Mental Health Services and Medicaid—to find subsistence.

Existing State Services- Issues

1. As outlined above in this section, insurance coverage for Autism treatment is almost nonexistent. Furthermore, there are scant federal resources dedicated to Autism intervention.

2. As a result, kids who might have had their Autism mitigated through early treatment, and who might have gone on to lead productive lives, instead continue to be dependent as adults and often turn to State programs—like Welfare, Mental Health Services and Medicaid—to find subsistence.

3. The State of Nevada has been late in recognizing this "passing of the buck" by the federal and private sectors.

Existing State Services- Findings

1. Before entering school, young children with Autism can qualify for assistance from Nevada Early Intervention Services (NEIS). Taking advantage of this early window of opportunity can yield the greatest benefit for each treatment dollar invested. Unfortunately, NEIS is under-funded to meet the needs of Nevada's growing Autism population.

2. The large school districts in the State were very slow to realize that they could ameliorate Autism, rather than just coping with it. Clark County School District has begun to invest in Applied Behavioral Analysis services for some of their

students and, as a result, is finding it easier and less expensive to educate these students as they progress in their treatment.

3. The 2005 Nevada Legislature considered and defeated proposed measures to roll-out Autism services. In the wake of the 2005 session, Mental Health and Developmental Services (MHDS) developed an ad hoc demonstration project to help children who have Autism co-occurring with intellectual delays. The high impacts of this project convinced the 2007 Nevada Legislature to provide it with long-term funding.

4. In recognition that many children have Autism without intellectual delays, the 2007 legislature also created a companion to the MHDS program within the Office of Disability Services. This program provides virtually the same services to children who do not qualify for the MHDS program.

The Nevada Legislature is asked make permanent the Autism intervention program currently funded in budget account 3266 in Office of Disability Services.

Existing State Services - Recommendations

1. The programs noted above are all in desperate need of additional funding. Given the current struggles with the State budget, it is recommended that their funding be retained in 2010-11at least at the legislatively approved levels for 2008-09.

APPENDIX E

Arguments In Support of Private Insurance Coverage of Autism-Related Services
Autism Speaks

Click here to view Appendix E (pdf)

APPENDIX F

Pennsylvania Autism Spectrum Disorders Mandated Benefits Review Panel Report

Click here to view Appendix F (pdf)

Screening and Diagnosis

Members of Screening and Diagnosis Subcommittee

Randy Figurski, MS CC-SLP
Chair

Subcommittee Members:

Diane Branson

Nevada State Health Division Autism Training and Technical Assistance

Catherine Armstrong

Nancy Sylvanie, Ph.D.

Shari Fyfe

Dr. Julie Smith-Gagen

Korri Ward
Parent, Rural Nevada
Nevada Autism Task Force Member

Dr. Johanna Fricke

Tiffany Kostelec

As approved by the Screening and Diagnosis Subcommittee on May 14, 2008

Screening and Diagnosis

Executive Summary

Children who begin early intervention prior to age 3 years have the best developmental outcomes.

The prevalence of Autism Spectrum Disorders (ASD) has increased significantly in recent years and is currently reported to be 1 in 150 according to the Centers for Disease Control [1] elevating the disorder to a major public health issue. Empirical evidence indicates that the better developmental outcomes occur for children who begin early intervention well before age 5 years, and the best outcomes occur for children under the age of 3 years [2, 3]. Although studies show that most parents of a child with ASD report a concern about their child's development prior to age 2 years, ASD is typically not diagnosed until 2-3 years after parents first notice the symptoms [4]. This continues to occur, even though screening tests can be used to reliably identify children at-risk for ASD at 18 months [5] and some researchers report tools which can be used to identify a child as young as 12 months of age [6]. Children in Nevada are not receiving an appropriate diagnosis of ASD in a timely manner due to many factors including, (a) limited use of developmental and autism-specific screening tools in medical and education settings, (b) lack of qualified personnel trained to make an ASD diagnosis, and (c) barriers such as lack of a medical home, cultural and linguistic diversity and/or socioeconomic status.

Summary of Issues/Findings

Issues:

Children are not being screened for ASD

Children referred to Nevada Early Intervention Services (NEIS) due to a suspected developmental delay are not routinely given an autism-specific screening tool at 18-months and 24-months of age.

- Nevada does not have a uniform system for identifying children who may be at risk of developmental delays and/or ASD. Lack of developmental surveillance and screening is a critical barrier to early identification of ASD.
- Pediatricians are encouraged by the American Academy of Pediatrics (AAP) to conduct developmental surveillance during well-child visits and developmental screening and Autism-specific screening on a periodic schedule (using standardized screening instruments rather than clinical judgment alone). Research on pediatrician practices, however, indicates lack of time, adequate reimbursement and lack of use of standardized developmental screening tools are barriers [7].
- The number of children identified with ASD in Nevada is only 50% of the expected number based on national prevalence rates of 1 in 150 [1].
- Children referred to Nevada Early Intervention Services (NEIS) due to a suspected developmental delay are not routinely given an autism-specific screening tool at 18-months and 24-months of age.

Children are not receiving a diagnosis of ASD in a timely manner

- National data on early identification indicates that most parents become concerned about their child's development between 15 and 18 months of age but may have difficulty getting their concerns taken seriously or acted upon. [8]. This often results in significant delays between the time parents raise the concern and the eventual diagnosis. Many parents report delays of two to three years, or longer. Results of a survey conducted by the Nevada Autism Summit in 2006 indicated that many Nevada parents share in that unfortunate experience [9].
- Many communities across Nevada do not have access to professionals who feel competent to diagnose ASD or who can devote the time necessary to provide in-depth assessment of an individual for treatment planning purposes.

Findings:

Nevada does not have an efficient means for tracking the incidence and prevalence of ASD in our state

Many children with ASD under the age of 6 years are receiving services under the developmentally delayed category leading to an under-reporting of ASD prevalence in Nevada.

- There is a significant lack of data on Nevada Autism prevalence and service utilization on which to base changes in policy, or the formation of new services, or to estimate resource capacity and needs across the State.
- The Individuals with Disabilities Education Act (IDEA) and the Nevada Administrative Code (NAC 388.430) allows children under age six to be made eligible for early intervention and early childhood special education services under a generic category of Developmental Delay (DD). While this is allowed by IDEA and NAC, it is not required and children with ASD may be made eligible under the ASD category. In Nevada many toddlers and preschool children with ASD are receiving services under the DD category. Therefore, the actual numbers of children with Autism Spectrum Disorders are underreported. Despite public agency assurances that individualized service plans are based on need and not eligibility category, parents frequently complain that children without specific ASD eligibility do not receive the specialized and intensive treatment services needed by this population.

Barriers exist which impact screening, diagnosis and delivery of services for individuals with ASD

- According to the U.S. Department of Health and Human Services (2005) [10] at least 60% of families in Nevada do not have a "Medical Home". This means these children do not have a personal doctor or nurse nor do they receive care that is accessible, comprehensive, culturally sensitive and coordinated. Families may access intermittent medical services for their children through hospital emergency rooms, but no one is monitoring the health or development of these children over time.
- There are significant challenges in ensuring that minority children in Nevada have access to developmental and autism-specific screening, diagnostic and treatment services. Children from culturally and linguistically diverse populations are being under-identified with ASD. According to the University of Nevada Center for Health Statistics and Informatics (draft report, 2008) [11], only seven percent of children receiving ASD services in Nevada are members of culturally and linguistically diverse populations.
- There is a lack of effective collaboration and coordination among public and

nonpublic agencies that provide ASD screening, diagnostic and intervention services for individuals with ASD leading to confusion for families who are accessing services through multiple layers of state and community agencies.

Lack of a "Medical Home" is a barrier to children receiving ongoing developmental surveillance and developmental screening services.

- Access to services is negatively impacted by factors such as the primary language spoken in the home (non-English speakers are much less able to know about or access services), location (rural vs. urban), socio-economic status (parents who can pay for services out-of-pocket can access more services), educational level (parents who can access information via print or the internet are better informed about available services and supports).
- Without the informed, written consent of the parent(s), the school district may not share information related to the eligibility or treatment plan of a child with Autism with others involved in the child's care, including child's primary care physician or other nonpublic professionals.
- Early intervention and early childhood special education services are historically under-funded in Nevada. The number of early interventionists and school district educators and therapists who are well-trained and experienced in providing services for individuals living with ASD does not meet the need for this rapidly growing disability group.

Recommendations

Screening

All children in Nevada, reguardless of race, ethnicity, primary language, education or socio-economic status should have access to ASD screening, diagnostic and treatment prior to age 3, and preferably before age 2 years.

- The Department of Health and Human Services will conduct an ongoing public awareness campaign to increase the awareness of the early signs of ASD, and increase access to developmental, behavioral and ASD- specific screening using multimedia methods.
- All children in Nevada will be screened with standardized developmental screening tools at specific intervals (i.e., at the 9-, 18-, and 24- or 30-month well child office visits) [12] as well as ASD-specific screening tools at age 18 months and 24 months regardless of whether a concern has been raised or a risk has been identified.
- Create web-based ASD information and education support services that feature a variety of ASD learning opportunities, audio-visual and print resources and interactive discussion forums to provide educational opportunities for parents of individuals with ASD and professionals working with individuals with ASD.
- Disseminate information advertising the statewide toll-free number for the Nevada State Health Division's Autism Training and Technical Support Center where families can access free developmental, behavioral and autism-specific screening for their child.
- Develop a statewide Neurodevelopmental Disorders Registry and designate Autism Spectrum Disorders as a reportable condition in Nevada for the purpose of determining the incidence and prevalence of this condition across our State.
- Improve statewide professional capacity for early identification of ASDs via: Training workshops on the use of standardized developmental, behavioral and ASD-specific screening tools for early care and education providers who have ongoing contact with children (e.g., community childcare providers, Early Intervention and Early Childhood Special Educators, Early Head Start and Head Start teachers).
- Embed best practice methods for early ASD identification and referral into pre-professional preparation courses in psychology, general and special education, and health and allied health courses (e.g., nursing, speech-language pathology, occupational and physical therapy).
- Improve coordination between state agencies responsible for developmental screening to increase efficiency and avoid duplication of efforts.
- Provide health care professionals (e.g., pediatricians and other physicians, nurses) access to training in the recognition of "red flags" associated with ASD,

the administration of screening tools and utilization of appropriate referral sources. The goal of this recommendation is to lower the age at which children are identified with ASD and other developmental disorders in Nevada with an ultimate goal of identifying children between 18 and 24 months of age.

- Increase the number of children and youth in Nevada who have access to a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent.

All professionals involved in the assessment of ASD should follow current best-practice guidelines.

Diagnosis and Eligibility

- ASD diagnosis, evaluation and assessment are conducted by a team of trained professionals experienced in identifying and assessing ASD. An ASD team should include a physician and a licensed clinical or school psychologist, a licensed speech-language pathologist, and a licensed occupational or physical therapist. Diagnosis of Autism is made by observation of a child over time across several meaningful settings and involving opportunities for the child to interact with familiar and unfamiliar adults and children. A careful history of the child and family (i.e., birth, medical, developmental, social and family histories) should be recorded and considered in a differential diagnosis of Autism.
- Create a University of Nevada Center of Excellence in Autism which includes representation from a variety of health and education departments. The Center will provide ongoing training and support to professionals and programs working with children and families living with Autism.
- Develop and disseminate statewide standards for ASD screening, diagnosis, and referral and develop and disseminate a comprehensive service delivery model to improve consistency and collaboration of services for individuals living with ASD across systems of care in Nevada.
- Develop a train-the-trainers model, in which professionals from diverse Nevada communities receive ongoing training in best practices in the diagnosis, assessment and treatment of ASD. The Autism Training and Technical Support Center will provide ongoing support to professionals in their home communities to encourage the development of local ASD diagnostic teams. These community professionals will, in turn, provide ongoing professional in-service training and technical assistance to improve the quality of educational and treatment services to individuals and families living with ASD.

An appropriate diagnosis should be available to children within 60 days, after parents contact a professional with concerns about ASD.

- Parents' concerns about their child's development will be taken seriously from the beginning. An autism-specific screening instrument will be given to the child at the time the parent expresses a concern (e.g., pediatrician's visit, early intervention intake visit). Procedures to obtain an appropriate diagnosis will also be started at that time ensuring that children will receive an appropriate diagnosis within 60 days of expressing their concerns to a professional.
- Ensure that each child who meets the criteria for one of the several Autism Spectrum Disorders will have Autism Spectrum Disorder recorded as his or her eligibility status. *The generic Developmental Delay status will not be used for children meeting the criteria for ASD.*
- State agencies and Nevada institutions of higher education will collaborate to ensure that all of Nevada's independent school districts and Nevada Early Intervention Services statewide will have appropriately trained Multidisciplinary Teams (MDT) to provide competent evaluation and assessment of ASD. With the family's informed consent, School Districts and Early Intervention Services will engage proactively with families to share the results of ASD evaluation and assessment with the child's primary care physician and other community professionals. Early Intervention Programs and School Districts will demonstrate that they have informed families of the availability of those services and have actively assisted families in obtaining a medical diagnosis and referral to other public and nonpublic services. A medical diagnosis of ASD permits families to pursue other services over and above the services required by the child's Individual Family Service Plan (IFSP) or Individual Education Plan (IEP).
- Reform medical insurance coverage to ensure that developmental and autism-specific screening is a covered service.

References

1. Center for Disease Control (2007) *CDC releases new data on autism spectrum disorders (ASDs) from multiple communities in the United States.* Retrieved February 20, 2007 from: http://www.cdc.gov/od/oc/media/pressrel/2007/r070208.htm.
2. National Research Council, *Scientific research in education*. 2002, Washington D.C.: National Academy Press.
3. Koegel, R. & Koegel, L. (2006) Pivotal response treatments for autism: Communication, social & academic development. Baltimore, MD: Paul H. Brookes.
4. Filipek, P., Accardo, P., Baranek, G., Cook, E., Dawson, G. et al. (1999). The Screening and Diagnosis of Autistic Spectrum Disorders. Journal of Autism & Developmental Disorders, 29, 439-484.
5. Baron-Cohen, S., J. Allen, and C. Gillberg (1992). Can autism be detected at 18 months? The needle, the haystack and the CHAT. *British Journal of Psychiatry, 138, 839-843.*
6. Bryson, S., et al. (2007). A prospective case series of high-risk infants who developed autism. *Journal of Autism and Developmental Disorders,* 37, 12-24.
7. Sices, L. (2007). Developmental screening in primary care: The effectiveness of current practice and recommendations for improvement. The Common Wealth Fund: Boston.
8. Lord, C. and R. Luyster (2005). Early diagnosis and screening of autism spectrum disorders. *Medscape Psychiatry & Mental Health*, 10(2), 1-6.
9. Ganz, C. and D. Vigil (2006) *Nevada Autism Summit Report*, University of Nevada, Reno: Reno, NV.
10. US Department of Health and Human Services (2005). *The National Survey of Children with Special Health Care Needs*. Retrieved July 1, 2008 from http:www.hhs.gov/.
11. Gagin-Smith, J.(2008) *Prevalence of autism in Nevada (draft report)*. University of Nevada Center for Health Statistics and Informatics: Reno.
12. American Academy of Pediatrics (2006). Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*, 118(1) 405-456.

APPENDIX G

Screening & Diagnostic Assessment Tools
Current as of July 31, 2008

Click here to view Appendix G Part I (pdf)
Click here to view Appendix G Part II (pdf)

Training, Certification and Applied Behavior Analysis

Members of the Training, Certification and Applied Behavior Analysis Subcommittee

Patrick M. Ghezzi, PhD, BCBA
Chair
Director, Behavior Analysis Program
Director, UNR Early Childhood Autism Program

Melanie Stevens
Staff

Committee Members

Jan Butz, PhD, BCBA
C.A.R.E. Educational Servoces

Amy Coyne
Clark County School District

Ron Leaf, PhD
Autism Partnership

Erik Lovaas, President
The Lovaas Center for Behavior Intervention

Debra Meinberg
Easter Seals, Southern Nevada

Cathy Mellor
Clark County School District

Troy Parks
Washoe County School District

Ann Drendel-Haas
Washoe County School District

Jody Silva.
Washoe County School District

Nancy Sylvanie, PhD

Matt Tincani, PhD, BCBA
UNLV

Michele Tombari
Parent, Southern Nevada

State of Nevada Autism Task Force Subcommittee on Training, Certification and Applied Behavior Analysis

Executive Summary

There is no question that Applied Behavior Analysis (ABA), or more precisely, Early Intensive Behavioral Intervention (EIBI), can lead to recovery for a significant number of young, pre-school-aged children with Autism Spectrum Disorder (ASD). The demand in Nevada far exceeds the supply of practitioners specializing in EIBI and credentialed by the nation's Behavior Analysis Certification Board (BACB). The state's two major universities, UNR and UNLV, are unable to provide sufficient numbers of specialized and credentialed practitioners of this sort. It is recommended that the Nevada System of Higher Education take immediate steps to rectify this situation by enhancing UNR's and UNLV's capacity to train undergraduate and graduate students for careers in EIBI. A necessary first step in this regard is to hire sufficient numbers of full-time, tenure-track faculty with the proper training, experience and BACB credential to teach and supervise students at UNR and UNLV in the science of behavior analysis and its application to the education and treatment of young children (as well as older children and adults) with ASD.

The demand in Nevada far exceeds the supply of practitiioners specializing in the field of Behavioral Sciences.

Findings showed that a significant number of young, pre-school aged children with ASD had achieved normal or average intellectual and educational functioning after several years of Early Intensive Behavioral Intervention.

Why Professional Certification in Applied Behavior Analysis?

Twenty years ago, research findings based on the methods Applied Behavior Analysis (ABA) were published by Ivar Lovaas at UCLA.[1] These findings showed that a significant number of young, pre-school aged children with ASD had achieved normal or average intellectual and educational functioning after several years of Early Intensive Behavioral Intervention (EIBI). Researchers since Lovaas have consistently reported the same positive outcomes.[2] In the light of this evidence, the United States Surgeon General declared in 1999 that ABA (or more precisely, EIBI) was the most effective treatment for young children with ASD. [3]

The United States Surgeon General declared in 1999 that ABA was the most effective treatment for young children with ASD.

The UCLA research was highly controversial because it showed that nearly 50% of the young children recovered from ASD. This finding conflicted with the common belief at the time that these youngsters were incapable of achieving typical, age-appropriate development. Little credence was given, then, to the notion that recovery from ASD was possible or that it was a realistic goal for these young children.

It was not long before parents became aware of the UCLA research and the hope of recovery it created for their own young children with ASD. A dramatic, nation-wide surge in the demand for EIBI specialists resulted. Parents soon discovered, however, that these specialists were in very short supply.

The situation was ripe for exploitation and ill-will. Parents desperately wanted services for their young children, thus becoming easy targets for persons who claimed expertise in EIBI without the proper training, experience, and supervision. It was clear that something needed to be done to protect parents and their children from deceitful claims and wayward practices and to also protect the profession from being cast by the public in an unfavorable light. A national movement to regulate ABA practitioners gained momentum, culminating in the creation of the Behavior Analysis Certification Board in 2000.

What is the Behavior Analysis Certification Board?

The mission of the Behavior Analysis Certification Board (BACB) is "to develop, promote, and implement a national and international certification program for behavior analyst practitioners." [4] In pursuing this mission, the BACB "has established uniform content, standards, and criteria for the credentialing process that are designed to meet (1) the legal standards established through state, federal, and case law, (2) the accepted standards for national certification programs, and (3) the best practice and ethical standards of the behavior analysis profession." [5]

The BACB credentials behavior analysis practitioners at two levels. The top level is Board Certified Behavior Analyst, or BCBA. Persons at this level must (1) hold a masters degree in behavior analysis, (2) have 225 classroom hours of graduate coursework in behavior analysis, (3) have 1500 hours of supervised field experience in behavior analysis, and (4) pass the Behavior Analyst Certification Examination. The second level is Board Certified Associate Behavior Analyst (BCABA). At this level, persons must (1) hold a bachelors degree, (2) have 135 classroom hours of undergraduate coursework in behavior analysis, (3) have 1000 hours of supervised field experience in behavior analysis, and (4) pass the Associate Behavior Analyst Certification Examination.

Persons meeting the degree, coursework, experiential, and examination requirements for the BCBA and BCABA credential must renew their certification every three years. This involves continuing education, which prominently includes completing advanced university courses in the philosophical, theoretical, basic and applied dimensions of behavior analysis.

The BACB does not currently credential practitioners working with young children with ASD. A task list specific to serving this population is available but is only advisory at this time. [6] The upshot of this is that BCBA's and BCABA's are not necessarily specialists in EIBI but may instead specialize in other areas where ABA has also proven to be incredibly effective (e.g., pediatrics, mental health, substance abuse).

It is important to acknowledge that practitioners working with young children with ASD who are not board certified may nevertheless have the training and experience necessary to provide EIBI. Most of these practitioners antedate the current credentialing process embodied by the BACB, and many of them play a central role in research, service delivery, and training and supervising persons to work intensively with young children with ASD. Professionals within the field are likely to know these persons by their fine reputations. Parents and caregivers are seldom privy to this information, however, which makes it extremely difficult for them to judge for themselves who may be qualified to treat their young child. A BCBA or BCABA credential is extremely helpful in this regard, and can ultimately make a crucial difference in the quality and eventual outcome of a child's education and treatment.

Are there Sufficient Numbers of BCBA's and BCABA's in Nevada?

One way to answer this question is to turn to Nevada's data base on the prevalence of young children with autism and to then turn to the data on the number of BCBA's and BCABA's in the state. With those two figures in hand, it would be easy to calculate the ratio of young children with ASD to the number of BCBA's and BCABA's to arrive at a gross measure of how well the state is meeting the demand for credentialed EIBT specialists. Unfortunately, there are two problems with this approach: The BCBA does not credential EIBI specialists, and the prevalence of young children with ASD living in Nevada today is unknown.

A second way to answer the question is take an incidence approach. The United States Census Bureau estimates that 183,437 children under 5 years of age were living in Nevada in 2006. [7] With that estimate in mind, the 2007 data base from the Centers for Disease Control and Prevention predicts that one in 150 children born in the United

States today will be diagnosed with ASD. [8]

What these facts portray is that there are roughly 1,223 children now living in Nevada under the age of five years who are or will be diagnosed with ASD. Bear in mind that this figure does not take into account the number of children born in Nevada each year. According to the 2002 Nevada Demographic and Health data base, 32,571 children are born each year in Nevada.[9] If one in 150 of these newborns is eventually diagnosed with ASD, then roughly 217 children are added each year to the state's population of young children with the disorder.

The BACB Certificant Registry currently lists 25 BCBA's and one BCABA for Nevada. [10] Of that total, 16 BCBA's reside in the Reno-Sparks-Carson City area, eight reside in the Las Vegas area (as does the one BCABA) and one BCBA resides in Deeth (a small town in Elko County). We hasten to add that the list is undoubtedly much shorter because the BACB does not credential EIBI specialists. That said, let us assume for the sake of argument that the 25 BCBA's are all EIBI specialists.

The BACB Certificant Registry currently lists 25 BCBA's and one BCABA for Nevada.

With a conservative estimate of 1,223 children in Nevada less than five years of age with an ASD diagnosis, there is roughly one BCBA for every 49 children. Are there sufficient numbers of BCBA's in Nevada to meet the current and future demand for EIBI specialists? The answer is a resounding NO.

Consider a typical EIBI program that schedules 40 hours per week of treatment for a young child with ASD. If 49 children participate in such a program under the supervision of one BCBA, then that one person would be responsible for supervising 1,960 hours of treatment per week, 7,840 hours per month, and 94,080 hours per year. This is clearly an impossible situation with dire consequences: Far too many young children with ASD in Nevada either go without EIBI or they receive marginal services that are unlikely to lead to normal or average intellectual and educational functioning.

What is the Current Status of Nevada's Training Programs in Behavior Analysis?

The opportunity to acquire the skills, knowledge and supervised experience necessary to meet the requirements for board certification in behavior analysis is limited in the state to the University of Nevada, Reno (UNR) and the University of Nevada, Las Vegas (UNLV).

The Department of Special Education at UNLV offers a BACB-approved five course sequence that meets the coursework requirements for the BCBA credential. Approximately 10 students currently participate in conjunction with pursuing their master's degree in special education. A small number of additional individuals are taking these courses as non-degree seeking students. Most of the degree and non-degree seeking students at UNLV are working in the ASD field as classroom teachers and program supervisors; only a few of them are specializing in EIBI.

The UNR Early Childhood Autism Program.[12] Opened in 1995, the program is capable of serving only six or seven young children and families with ASD in the Reno/Sparks community at a time.

Supervised field experience is provided by BCBA's on the faculty at UNLV and by BCBA's working in the community. There are reportedly two major problems with this arrangement. The first is that there are roughly four non-university BCBA's active in the Las Vegas community and all of them report being far too busy with their own private enterprises to supervise UNLV's students on a regular or consistent basis. The second problem is that of the four BCBA's on the special education faculty at UNLV, three resigned this spring, 2008. It is evidently doubtful that the three positions will be filled in the near future, if at all.[11]

The situation is comparatively better at UNR. The Department of Psychology at UNR is home to the Behavior Analysis Program, which offers two graduate degrees, MA and PhD. The program is accredited by the Association for Behavior Analysis International and its graduate curriculum is BACB-approved. The Behavior Analysis Program is also distinguished by operating the only university-based EIBI program in Nevada, the UNR Early Childhood Autism Program.[12] Opened in 1995, the program is capable of serving only six or seven young children and families with ASD in the Reno/Sparks community at a time.

The Behavior Analysis Program at UNR consists of 40 graduate students and five faculty members. Only one of the five is fully funded by state-appropriated resources, however. The remaining four faculty members each hold full-time appointments yet are funded by the state at a half-time rate and thus must rely on grants and contracts to bring their salaries up to a full-time equivalent. Two of the five faculty members are BCBA's, however, only one of them is an EIBI specialist. Supervision for board certification purposes and with regard to EIBI is provided, then, by a single (and .50 state funded) faculty member, who supervises 3-4 graduate students and about 25 undergraduate students per year in the context of UNR's Early Childhood Autism Program.

It is clear that UNLV's and UNR's training programs in behavior analysis are woefully underfunded and thus incapable of supplying the state with sufficient numbers of BACB credentialed, EIBI specialists to meet the current and future demand for their services.

A Final Comment

While the emphasis throughout this report has been on young, pre-school-aged children with ASD, it is vitally important to understand that the methods of ABA are remarkably successful with older children and adults with ASD. The decision to focus on young children with ASD is based on volumes of research showing that intensive behavioral intervention is most likely to lead to full recovery when it begins early in a child's life. Research suggests that full recovery for older children and adults is less likely, and yet research also shows that many of these individuals make tremendous strides in their development when the methods of ABA are practiced with them.

While the emphasis throughout this report has been on young, pre-school-aged children with ASD, it is vitally important to understand that the methods of ABA are remarkably successful with older children and adults with ASD.

Recommendations

The hopes and dreams that thousands of parents have for their young children with ASD in Nevada rests squarely with the state's capacity to produce a workforce of BACB credentialed specialists in EIBI. Greater numbers of undergraduate and graduate students must have the opportunity to receive the academic training and supervised practical experiences necessary to achieve this end. The Nevada System of Higher Education must insist, therefore, that UNR and UNLV devote their state-appropriated resources to hiring full-time, tenure-track faculty in the science of behavior analysis and its application to the education and treatment of young children with ASD.

The demand in Nevada far exceeds the supply of practitiioners specializing in the field of Behavioral Sciences to address this critical shortage. A systematic plan needs to be implemented to:

1. Increasing Nevada's capacity to produce a sustainable workforce of behavioral analysist credentialed by the nation's Behavior Analysis Certification Board (BACB) to serve individuals of all ages living with Autism Spectrum Disorders across their lifespan.

2. Support Nevada's system of Higher Education to provide undergraduate and graduate students access to academic training and supervised practical experiences needed to achieve this end.

3. Enhance UNR and UNLV's ability to devote their state-appropriated resources to hire faculty who specialize in the field of behavior analysis through the Psychology departments.

References

1 Lovaaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*, 3-9.

2 Matson, J. L., Benavidez, D. A., Compton, L. S., Paclawskyi, T., & Baglio, C. (1996). Behavioral treatment of autistic persons: A review of research from 1980 to the present. *Research in Developmental Disabilities*, *17*, 433-465. See also Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G, & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, *26*, 359-383; Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four year outcome and predictors. *American Journal on Mental Retardation*, *110*, 417-438.

3 U.S. Department of Health and Human Services (1999). *Mental health: A report of the surgeon general*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

4 www.bacb.com

5 www.bacb.com

6 www.bacb.com

7 www.factfinder.census.gov/servlet/ACSSAFFFacts?

8 www.cdc.gov/ncbddd/autism/overview.htm

9 www.ehd.org/health_state_data.php?stateno=29

10 www.bacb.com

11 Matt Tincani, PhD, BCBA (personal communication, June 6, 2008)

12 www.unr.edu/psych/autism

Building the Workforce To Support Individuals with A.S.D.

Nevada Autism Taskforce Workforce Subcommittee

Final Report

June 3, 2008

Matt Tincani, Ph.D.,
UNLV

Chair

Subcommittee Members:

Angie deBraga

Angela Flora
Washoe County School District

Michael Harley
Compliance and Monitoring
Clark County School District

Mary Liveratti
Deputy Director
Department of Health and Human Services

Jan Marson
Occupational Therapist
O.T. Play Room

Jacque Matteoni
Washoe County School District

James Ohrenschall
Nevada State Assemblyman

Nancy Sylvanie, Ph.D.

Shannon Ward
Washoe County School District

Building the Workforce To Support those with Autism Spectrum Disorders

Executive Summary

The surge of people diagnosed with Autism Spectrum Disorders (ASD) in Nevada demands a workforce of highly skilled professionals.

The surge of people diagnosed with Autism Spectrum Disorders (ASD) in Nevada demands a workforce of highly skilled professionals. Recent budget cuts to the Nevada System of Higher Education proposed by Governor Jim Gibbons will permanently cripple programs to train ASD professionals, programs which are already underfunded by any reasonable standard. Steps to remedy the current situation include increasing funding for professional training programs in critical shortage areas, such as applied behavior analysis, and developing a 10-year strategic plan to bolster Nevada's workforce. Without these measures, the shortage of qualified professionals is likely to worsen, making services for people with ASD even more inadequate.

People with ASD require intensive supports across the lifespan.

What is the Autism Workforce in Nevada?

People with ASD require intensive supports across the lifespan. These include early intervention, special education, applied behavior analysis, speech / language therapy, and services to promote successful transitions to adulthood. A well-trained workforce of direct and peripheral service providers is needed to address the intensive needs of people with ASD in Nevada.

Nevada must develop a 10-Year Strategic Plan to Address Nevada's ASD Workforce Needs.

- **Direct Service Providers'** primary job responsibilities involve supporting people with ASD and related disabilities.

- **Peripheral Service Providers'** primary job responsibilities do not involve supporting people with ASD and related disabilities; however, they interact with individuals on the spectrum during the course of their professional duties.

The intensive support needs of individuals with ASD, in combination with Nevada's rapidly growing population, underscore the state's inadequate resources to sustain an effective workforce.

Direct Service Providers

Applied Behavior Analysts
Early Intervention Specialists
Occupational Therapists
Speech/Language Therapists
Physical Therapists
Adaptive Physical Education Teachers
Special Education Teachers
Behavior Interventionists
Case Managers
Job Coaches
Specialized Physicians (e.g., neurologists, psychiatrists)

Peripheral Service Providers

Law Enforcement Personnel
Emergency Responders
Non-Specialized Physicians (e.g., general practitioners)
Respite Workers
Foster Care Workers
Welfare personnel
Child and Family Services Personnel

What is Nevada's Current Workforce Capacity with Respect to Autism?

A fiscally stable higher education system is necessary to support Nevada's ASD workforce. The intensive support needs of individuals with ASD, in combination with Nevada's rapidly growing population, underscore the state's inadequate resources to sustain an effective workforce. Nevada's inadequate workforce resources are evidenced by the following:

- In 2007, the Nevada Legislature funded the state's colleges and universities at just 84.5 percent of the national average[1].

- Nevada's university system sustained a 4.5 percent budget cut in 2008[2]. Additional budget cuts of over 14 percent have been proposed by Governor Jim Gibbons by the end fiscal year 2009[7]. Budget cuts have already resulted in layoffs and hiring freezes at Nevada's colleges and universities.

- At UNLV, the state's largest research university, the impacts of budget cuts include delays in hiring new faculty and student advisors, suspension or elimination of new programs, larger class sizes, and delays in updating classroom technology[3]. Similar negative impacts are expected at Nevada's other colleges and universities.

- Budget cuts at Nevada's universities and colleges hinder the hiring and retention of faculty who train ASD direct service providers. If implemented, the proposed budget cuts, totaling almost 20 percent, will decimate programs that train ASD professionals, including educators, early interventionists, and behavior analysts[7].

Lack of capacity to sustain an effective ASD workforce is reflected in chronic shortages across all Nevada direct service provider professions.

As Nevada's population continues to grow and increasing numbers of children are diagnosed with ASD, it is clear that the state's current higher education resources are inadequate to meet personnel preparation needs.

What are the Current Workforce Deficits and Needs in Nevada?

Lack of capacity to sustain an effective ASD workforce is reflected in chronic shortages across all direct service provider professions. The following statistics illustrate the state's chronic workforce shortages:

- Students with ASD served in Nevada's school programs jumped from 1,779 in 2005 to 2,559 in 2008, an increase of 69%[4].

- 43 Nevada school programs for students with ASD were staffed by substitute teachers who lacked credentials and training to teach students with ASD in 2008[4].

- 60 additional school programs were staffed by teachers who were fulfilling the requirements of the Nevada autism endorsement, but who were yet not qualified to teach students with ASD[4].

- The Clark County School District had 34 unfilled speech language pathologist / speech language therapist positions in 2007[5].

- Only 25 Board Certified Behavior Analysts resided in Nevada in 2008[6].

- Nevada's school districts, including Washoe County, pay teachers significantly below regional averages[8], contributing to high turnover rates. Lack of professional incentives, including tuition reimbursement, further erodes the pool of qualified educators.

- Formalized services to enable adults with ASD to secure supported employment and live independently are basically non-existent. There are currently no professional training programs which specialize in the adult population.

Chronic workforce shortages produce inadequate services for people with ASD. Primary professionals cannot learn how to effectively support individuals on the spectrum through "on the fly" job training. Rather, ASD is a complex disorder that demands personnel with specialized training.

Consequences of declining support for higher education programs are severe. For example, untrained substitute teachers cannot provide effective behavior support to children with ASD, resulting in higher rates of problem behaviors, expensive and restrictive school placements, and unnecessary stress for families.

Consequences of declining support for higher education programs are severe. For example, untrained substitute teachers cannot provide effective behavior support to children with ASD, resulting in higher rates of problem behaviors, expensive and restrictive school placements, and unnecessary stress for families. Parents and service providers must pay for expert assistance from professionals in other states, such as California, further eroding Nevada's tax base and placing unreasonable financial burdens on families and service providers to pay for out-of-state services.

Addressing Nevada's workforce shortage across the critical areas is not just a matter of "spending smarter" with existing state resources. Both current and future programs require stable financial support for training of professionals to serve Nevada's burgeoning population of people with ASD.

Action Steps to Sustain an Effective Autism Workforce

Much can be done to improve Nevada's autism workforce. The following concrete steps will enhance Nevada's autism workforce capacity:

Increase Funding for ASD Programs in Critical Shortage Areas.

- **Increase Funding for ASD Programs in Critical Shortage Areas.** Direct service provider professions with critical shortages include special education, speech/language therapy, applied behavior analysis, and adult vocational services. The Nevada Legislature must create line item budgetary funding for critical shortage area programs at UNLV, UNR, and Nevada's other colleges. Funding would support the hiring of faculty to train direct services providers, tuition for students, and infrastructure to support programs.

Maintain Funding for Nevada's System of Higher Education at Parity with the National Average.

- **Maintain Funding for Nevada's System of Higher Education at Parity with the National Average.** Budget cuts to the Nevada System of Higher Education compromise existing and future programs to train direct services providers. As one of the fastest growing states in the nation, it is critical for Nevada's System of Higher Education to keep pace with increasing demand for ASD support professionals. Maintaining a reasonable level of funding for Nevada's System of Higher Education will help to ensure that programs continue and grow.

Create Incentives for ASD Professionals to Stay in Nevada.

- **Create Incentives for ASD Professionals to Stay in Nevada.** To stem the flow of ASD professionals out of state, provide incentives, such as signing bonuses and tuition reimbursements, for professionals to remain in their current positions. Support Alternative Route to Licensure (ARL) Programs for teachers to attain autism endorsements. Initiate professional certification for paraprofessionals working with students with ASD to enhance the quality of classroom instruction.

Initiate Professional Training Programs that Target Adult Nevadans with ASD.

- **Initiate Professional Training Programs that Target Adult Nevadans with ASD.** Services that cater to adults with ASD are almost non-existent in our state. Many adults with ASD, particularly higher functioning individuals, are capable of working and living independently with professional support. Programs that target professionals who work with older populations will increase the capacity of adults to live and work more independently.

Secure Federal Funding to Support Professional Training Programs.

- **Secure Federal Funding to Support Professional Training Programs.** Federal assistance is available to defray the costs of ASD professional training programs. The Nevada System of Higher Education could secure federal funding to match state revenues expended on ASD programs. Potential sources of federal monies include competitive grants and contracts from the U.S. Department of Education and the U.S. Department of Health and Human Services. Nevada System of Higher Education colleges and universities should collaborate for procurement of funds to support collaborative programs across units.

Develop a 10-Year Strategic Plan to Address Nevada's ASD Workforce Needs.

- **Develop a 10-Year Strategic Plan to Address Nevada's ASD Workforce Needs.** Nevada's population will change dramatically in the next ten years. Ongoing planning is necessary to understand the changing demands for ASD professionals. The Nevada Autism Taskforce should develop a 10-Year Strategic Plan to address the state's needs for both primary and peripheral ASD service providers. The strategic plan should include ongoing and formal assessments of professional preparation needs.

References

1. As Reported February 1, 2007 in the Las Vegas Review Journal, *HIGHER EDUCATION: Health Sciences Center at forefront of higher education issues*, by Lawrence Mower.
2. As Reported March 29, 2008 in the Las Vegas Review Journal, *Sales plunge, worsening budget woes*, by Sean Whaley.
3. *Summary Points on UNLV 2007-2009 Biennial Operating Budget – Governor's Reductions*, UNLV Institutional Planning, January 18, 2008.
4. *Commission on Professional Standards Statewide Autism Data*, Nevada Department of Education, February 2008.
5. *Nevada School Based Speech Pathologists/ Speech Therapists: Statewide statistics: 2006/2007*.
6. *Behavior Analyst Certification Board Certification Registry*, April 15, 2008.
7. *Memorandum to NSHE Board of Regents, Magnitude of Budget Cuts*, Chancellor Jim Rogers, May 29, 2008.
8. *Washoe County Teacher Salary Schedule 2007-2008.* Washoe County School District.

Adult Services

PART I: TRANSITION
PART II: EMPLOYMENT
PART III: COMMUNITY INCLUSION

Approved by the Transition, Employment and Community Inclusion Subcommittee on June 27th.
Submitted to Nevada State Autism Task Force on June 30th.

Table of Contents

Transition, Employment and Community Inclusion Subcommittee

Flo LaRoy, Chair
Parent of Individual with ASD
Nevada PEP

Subcommittee Members

Tammy Garrison
Parent of an Individual with ASD

Scott W. Harrington, Ph.D., BCBA
Youth Transition Director
Research and Educational Planning Center
UNR College of Education

Barbie Lauver
Asperger's Syndrome Support Group

Jessica and Angel Lomboy
P.A.L.S. Partners for Autonomy in Life Skills

Joan Shaffer
President
Act Now Nevada

Korri Ward,
Parent, Rural Nevada
Nevada Autism Task Force Member

Melissa Pegg
Project Facilitator
Transition Services
Clark County School District

Tessie Rose, Ph.D.
Department of Special Education
University of Nevada, Las Vegas

Suzanne A. Thomas

Kathy Treants
Transition Coordinator
Nevada PEP

Summary of Best Practices for Youth and Young Adults with Autism in Transition

Introduction by Scott W. Harrington, Ph.D., BCBA[1]

"Society loses out if individuals with Autism Spectrum Disorders are not involved in the world of work or make other kinds of contributions to society"
Grandin & Duffy (2004, p.vii)

The unique needs of individuals on the autism spectrum and their growing numbers require an expanded/service support network with more options.

This document is a summary of a comprehensive review of best practices in transition for youth on the Autism Spectrum (ASD). This is a working document and subsequent versions will include new programs. The complete document (Harrington_08), with links to many resources and references can be found at (Case sensitive password: Scott) http://homepage.mac.com/sharring/ASDTransition/FileSharing3.html

Information was collected through a scientific literature review (e.g., ERIC, Education Abstracts, and PsychINFO) of peer-reviewed publications and supplemented with a review of websites that claim to provide *best practices* for transitioning youth with ASD. "Best practices" is defined as projects that provided outcome data where individuals with autism were competitively employed and/or attending a post secondary educational institution (PSE), however, the quality of the placement was not evaluated in this review.

The following assumptions were made when compiling the research. These include: 1) An inclusive environment is optimal for youth with disabilities; 2) Individuals with disabilities are "employment ready" requiring a *good fit* between ones skills and job demands; and, 3) self-determination, reflected in consumer choice, leads to positive adult outcomes. Although indicated as assumptions, these are well supported in the research on transition for youth with disabilities. The unique needs of individuals on the autism spectrum and their growing numbers require an expanded/service support network with more options.

1 Dr. Scott Harrington is from the Nevada University Center for Excellence in Disabilities NV-UCED. He can be reached at sharring@unr.edu for suggestions and comments.

Effective Methods

The literature refers to multiple debates and discussions on the importance of "specialized and efficacious treatments and methods." Federal requirements in the No Child Left Behind (NCLB) Act resulted in substantial funding for programs that are "evidence-based," requiring certain data are collected, in certain ways, which show improvements. This is particularly true with ASD because of the enigmatic behavioral patterns and inexplicable increases in the prevalence of the disorder.

The Autism Society of America addresses effective methods with the Treatment Guided Research Initiative or TGRI (2007). This approach, according to the authors, is about "NOW and HOW." It is based on the premise that "we need to make low-risk treatments as widely available as possible, and that we need to combine providing treatment with doing science and research to ask '*how*' so that learning from outcomes and successes can become a major portion of our research efforts."

From a practical and collaborative approach, Wehman (2002) reported to President's Commission on Excellence in Special Education Transition Task Force meeting, and stated "Competitive employment history is one of the most powerful contra-indicators for youth ultimately depending on SSI long-term benefits" (p.194). Therefore, students need to attain competitive employment *before* leaving school. He indicated that this could be best accomplished via partnerships between school personnel and staff from the state-federal vocational rehabilitation program, as well as other community agencies.

Transition Planning

The movement from a system of *entitlement* in federally mandated programs (i.e., IDEA, IEPs, 504s, etc.) to a system of *eligibility* (i.e., Vocational Rehabilitation, Disability Resource Centers, Social Security, Medicaid, Independent and Supported Living Centers, etc.) has caused turmoil in many individuals and families. This tumultuous period of transition can be improved. While entitlement to public education ends at 18, the IDEA requires that transition planning begin at 16, becoming a formal part of the student's IEP. The Autism Society of America: Life After High School provides those with Internet access an invaluable resource, which discusses Transition Planning, Individualized Transition Plans, and Thinking about Transition. This resource is designed specifically for students with autism, and begins planning in Middle School, an early-intervention philosophy that has become more popular recently.

Alwell and Cobb (2006) published a meta-analysis of 164 studies on transition, evaluating the efficacy of the use of specific transition interventions across educational environments, disability types, ages, and genders. The first intervention that had a

significant impact was directly tied to transition planning, that is, identifying several strategies to promote student and parent involvement in the transition process. The more the student and parents are involved, the better the outcome reflected in increased employment earnings. Person-centered planning, self-determination training, knowledge of available services, student independence and interdependence, job application completion, career choice knowledge, and acquisition of request for breaks were all influential variables that resulted in positive outcomes. Several of the studies evaluated self-determination, in its own right. The authors report that asking for help, respecting the preferences of others, self-advocacy, acquisition of problem solving skills, and maintaining a positive attitude were all related to positive outcomes.

Person-centered planning, self-determination training, knowledge of available services, student independence and interdependence, job application completion, career choice knowledge, and acquisition of request for breaks were all influential variables that resulted in positive outcomes.

With focusing on quality of life, Gerhardt (2007) wrote a brief article on effective transition planning, and made several recommendations. These include: a) considering all learners to be "employment ready"; b) viewing first jobs a learning experiences; c) promoting creativity in job development; c) providing co-worker training; d) developing active ties with the business community (p. 26).

Transition to Employment

Temple Grandin (2008) reported that during her travels to many autism conferences, she observed many sad faces of people with autism who have successfully completed high school or college but were unable to make the transition into the world of work. In her article, she emphasized the importance of a "gradual transition" from an educational setting into a career. The article describes the slow steps that she took, and how influential people "recognized my talents and tolerated my eccentricities." Also, she stated a common theme found in good placements, which is "many successful people with autism have turned an old fixation into the basis of a career." She also mentions that the "freelance route" has enabled people with autism to be successful and exploit their talent area (e.g., perfect pitch, mechanical ability, artistic talent, etc.).

Delaware has long been in the forefront of meeting the needs of children and adults in the autism spectrum. The state began offering a statewide program 25 years ago and the Special Populations program for adults in 1989 (Autism Society of Delaware, 2005). The Autism Society of Delaware (ASDL) conducted a comprehensive study that evaluated the best practices for serving adults with autism in the United States. The authors operationalize "best practices" as "those services that are appropriate, flexible, highly individualized, and have a good cost-benefit ratio" (p.3).

A common theme in successful transition projects is the ability of the job developer, potential employer, the individual with the disability, and his/her support team to identify

the skills, interests, abilities, passions, and supports needed to be successful. The more the alignment between these items and the job responsibilities, the better the fit, and the more likely the placement will be successful. Winter-Messiers et al. (2007) defines Special Interest Areas (SIAs) as "those passions that capture the mind, heart, time, and attention of individuals with AS [Autism Spectrum], providing the lens through which they view the world" (p.70). These SIAs occur in over 90% of the children and adults with AS, and may be trains, dinosaurs, videogames, Disney movies, or the more eccentric, vampires, saxophones, goats, spiders, or toilets. Despite the object, a special interest enables them to achieve quite extraordinary levels of performance in a certain area (Asperger, 1944/1991, p. 45). The SIAs can be integrated in school with academics, motivating behaviors, learning about non-preferred classroom topics, and most importantly to this review, create a school-based related to the SIA (Winter-Messiers et al., 2007).

A common theme in successful transition projects is the ability of the job developer, potential employer, the individual with the disability, and his/her support team to identify the skills, interests, abilities, passions, and supports needed to be successful.

Customized Employment and other Innovative Models

In 2001, the U.S. Department of Labor, Office of Disability Employment Policy (ODEP) funded the Customized Employment (CE) Initiative. Six different initiatives were funded to document effective CE strategies for individuals with disabilities. Customized Employment, an evolved *Supported Employment*, is "a flexible process designed to personalize the employment relationship between a job candidate and an employer in the way that meets the needs of both" (ODEP, 2008). One of the CE recipients was the Rural Institute at the University of Montana, which has been a leader in the area of transition planning since 1995 (University of Montana Rural Institute).

The applicability of CE to individuals with autism is startling, simply because the eccentricities observed, often seen as *inappropriate*, can be viewed as strengths. For example, the obsessive classification and ordering via numerals or alphabetically and need of a quiet environment would be ideal for shelving books in a library. Myles and Smith (2007) wrote an introduction to a special issue of *Focus on Autism and other Developmental Disabilities*, where special interest and individual strengths are presented.

In an innovative approach to evaluating job preference, Ellerd, Morgan, and Salzberg (2006) examined correspondence between video CD-ROM assessment program, community jobs observed during employment site visits, and photographs of employment sites. The researchers reported data that showed a strong correspondence between the CD-ROM program and preference with community visits (85%), as well as with the photographs (82.5%)

Another innovative project, researchers interviewed the supervisors of 14

"successfully employed" individuals with autism (i.e., employed at least six months), and supplemented the data with worksite observations to examine their supervisory practices and perceptions of employees with autism (Hager & Cooney, 2005). The supervisors evaluated their employees highly, and qualitative analysis found that a set of specific supervisory accommodation strategies were commonly associated with successful supervision. These strategies include maintaining a consistent schedule and job responsibilities, using organizers to structure the job, reducing idle or unstructured time, being direct when communicating with the employee, and providing reminders and assurances (Hager & Cooney, 2005).

University and community college campuses offer much more than an academic degree; they offer opportunities for individuals to interact and socialize with same age peers, participate in engaging social events, live in residence halls, learn about careers, healthy lifestyles, independent living, and academic life.

Transition to Post-Secondary Education

The recent changes in philosophy about young adults with autism attending colleges and universities are significant. More and more universities are opening their doors to individuals with significant disabilities, but more importantly, these options are being discussed in an open forum. University and community college campuses offer much more than an academic degree; they offer opportunities for individuals to interact and socialize with same age peers, participate in engaging social events, live in residence halls, learn about careers, healthy lifestyles, independent living, and academic life. A well-publicized program, although expensive, is located at the College of Education in the University of Iowa is the Realizing Educational and Career Hopes (REACH). Other programs across the United States are increasing in popularity, such as the PACE program at National Louis University (Chicago), the Venture program at Bellvue Community College (Washington), Pathways at UCLA (California), the Threshold program (Massachusetts), the College of New Jersey, Mason LIFE at George Mason University, Minnesota LIFE College, and several others.

It has been empirically established that there are positive relationships among disability, level of education, and adult employment (Reis, Neu, & McGuire, 1997). The representation of students with disabilities in higher education has risen to about 20% (Wehman, 2002), and the fastest growing population in university settings are individuals with disabilities. Areas that can be improved include supporting students with disabilities to complete their degree, transitioning from PSE to employment, and most importantly, professional development and training for faculty and administrators to ensure a quality PSE experience for students with disabilities.

International Efforts

The Autism Source in the UK produced a document that listed the colleges for students with autism and Asperger syndrome. They indicated that some of the colleges "take students as young as 15 years but all take students over 19 years." This seven-page list

should be used not as a resource, but rather of an example of an agency that actively encourages young adults with ASD to attend PSE.

Note that the transition services begin for youth at the age of 14 in England and Wales.

The National Autistic Society produced a helpful resource that helps youth with autism and their families with transition. Note that the transition services begin for youth at the age of 14 in England and Wales. This document outlines roles and responsibilities for professionals, the child, parents/careers, LEA, Head Teacher (principal), career centers, school staff, social service departments, and other agencies. Another unique service in the UK is the "Prospects" program, the NAS's employment service, designed specifically for youth with autism and Asperger syndrome. They assist individuals transitioning to work and continuing post-secondary education. This program provides support in the workplace to people with ASD through the government's Access to Work structure, and there is no cost to the employer for the following services: orientation to the employee, identification of training needed, job analysis, including guidelines or breakdown of each task within the job; structure, including breakdown of the day and creating time plans; disability awareness training for colleagues; social training awareness and instruction on the unwritten rules of the workplace; development of an effective working relationship between the employee and the line manager (Barnhill, 2007; National Autistic Society).

Transition Resources

The most comprehensive resource for transition issues for youth with disabilities is the Division for Career Development and Transition (DCDT). Although the resource is not designed for specifically for transitioning youth with autism, there is a myriad of resources, publications, and updates that are available for the advocate.

The Treatment and Education of Autistic and related Communication-handicapped CHildren (TEACCH) at the University of North Carolina, Department of Psychiatry has been identified as a best practice site (Keel, Mesibov, & Woods, 1997). The program was established in the early 1970's and has received substantial funding for all ages of youth on the ASD. This program offers an insightful *Strategies for Surviving Middle School with an Included Child with Autism,* with several specific recommendations. The most valuable resource, which can be used by all parents, is the *Family Reference Guide to Services for Youth and Young Adults with Autism*. Although it is designed for individuals in North Carolina, the Flow Chart, Step-by-Step Process, Checklists, Helpful Hints, and many other parts are invaluable.

The nation's visionary in transition for young adults with autism is Delaware. In 2006 the Autism Society for America (ASA) held its conference, where multiple sessions

were presented, one of which was the "Delaware Model." Follow this link for access to an audio file of the presentation. The ASA has a creative "Career Center" website that is designed to members of the autism community in seeking employment opportunities, as well as prospective employers/recruiters seeking qualified candidates to fill vacant positions. There are many options at this center, however there are no data to evaluate its effectiveness and frequency of use.

The Rehabilitation Services Administration (RSA) at the U.S. Department of Education report concern about the ratio of unsuccessful to successful closures for people with autism: In 2005, unsuccessful closures were about 1 1/2 times greater than successful closures, suggesting systemic and/or programmatic barriers in the VR stem specific to individuals with ASD.

The Rehabilitation Services Administration (RSA) at the U.S. Department of Education (USDE) held the 32nd Institute on Rehabilitation Issues (IRI), and published a resource titled, *Rehabilitation of Individuals with Autism Spectrum Disorders* (Dew & Alan, 2007). This comprehensive, 149-page document discusses Transition Planning, Accessing the vocational rehabilitation (VR) system, Supporting Successful Employment, and Challenges/Recommendations. The authors report concern about the ratio of unsuccessful to successful closures for people with autism: In 2005, unsuccessful closures were about 1 1/2 times greater than successful closures, suggesting systemic and/or programmatic barriers in the VR stem specific to individuals with ASD (p.*vii*).

Summary

Over a decade ago, Wehman (1995, p. *x*) reported, "the time has passed for individuals with autism to be sitting in segregated schools, residential facilities, or adult activity centers all day long, performing meaningless tasks… to be relegated to earning a dollar a day in a sheltered workshop or to be confined to a 'day treatment' center." Some states, like Delaware, have prioritized transition services for youth with autism, and the young adults have integrated into the community while offering businesses their skills and talents. Other states, like Nevada, have waited and watched.

This literature review contains peer-reviewed articles and web-based resources that delineate best practices for youth and young adults on the ASD that are transitioning to work or PSE environments. An invaluable resource, the *Best Practices for Serving Adults with Autism* identified best practices across the United States, and made only one working assumption (Autism Society of Delaware, 2005). The report stated, "We assume that each individual will spend approximately 40 hours per week engaged in meaningful activity outside the home, with at least 20 hours of this being gainful employment. This is regardless of where an individual may live or what she or she may do across the day" (p. 6).

The Division on Career Development and Transition (DCDT) published a position statement on preparing personnel in transition (Blalock et al., 2003). Despite transition personnel preparation being recognized as a top research priority for the nation, a

majority of states were deemed to be out of compliance in meeting the IDEA's transition requirements (Williams & O'Leary, 2001). The esteemed authors provide a) the broader context for transition personnel preparation; b) what should be taught: core content; c) recommendations for personnel preparation programs; d) implications for educational policy, practice, and future research (Blalock et al., 2003).

A common thread across resources is an emphasis on individual choices and preferences. From the color of paint on one's walls, to the job choice, to who is a housemate, individual preferences must be honored. Transitions for youth with autism need to be planned and carried out gradually, and it does not work for too many factors to change at once. The Judevine Center in St. Louis, MO reported that students leaving the school program might have had job placements in the last year of school were required to give them up, as they were not allowed to transition with the job. This is common with school districts around America. Successful transitions to employment or PSE are done gradually, where the individual makes brief, non-stressful visits and has a positive experience. Information should be provided in a schedule format, allowing for repeated access by the individual, such as in written or picture form. Staff should be prepared and educated prior to the visits, and every effort should be made for a good fit between the staff and individual.

An adapted version (for Nevada) of the Delaware Best Practices review of exemplary programs indicates that "Best Practice" requires:

Building a local Nevada focus. Our program and providers should be "homegrown," focused on our local priorities, specific individual's needs, and directed by a simple organizational structure with minimal administrative hierarchy. Programs must be responsive to local needs and not to distant administrations.

1. Integrating activities seamlessly throughout the day and week, across the areas of domestic life, employment, recreation, and social relationships. That is, the person's life should not be divided into compartments such as "residential services" and "employment services" for which different groups of staff have different responsibilities.
2. Adopting a common philosophy. There must be a clear, shared philosophy that is embraced by all of the stakeholders of the support program. Staff at all levels must not only articulate the philosophy, but "live" it. This enhances consistency in the quality of services delivered.
3. Establishing funding that is diversified and sustainable, using ALL resources within the community (e.g., small business loans, food stamps) thus promoting flexibility and program survival. It is integrated and coordinated without the constraints of an elaborate administrative "system."
4. Building a local Nevada focus. Our program and providers should be "homegrown," focused on our local priorities, specific individual's needs, and directed by a simple organizational structure with minimal administrative hierarchy. Programs must be responsive to local needs and not to distant administrations.
5. Adopting a family-driven, family-directed approach. The individual, with his or her own perspective and preferences is part of a family and must be recognized as such.
6. Adopting procedures for effective and efficient use of all resources including fiscal and human resources across persons served.
7. Incorporating systematic evaluation and accountability. This takes place from the individual all the way to the systems level. It should reflect the local ecology.

Number of Students with ASD served by Nevada School Districts

Two districts provided data on the number of students with a primary diagnosis of ASD. Data from other districts in Nevada was unavailable for review.

- **Clark County School District**
  There are 308 students aged 14-21 with a primary diagnosis of Autism within the Clark County School District. Fifty (50) of those students are 18 – 21 years old.

- **Elko County School District**
  Per the Dec.1 count there are 30 students in the Elko County School District identified with Autism. Nine (9) of the students are between the ages of 14 - 21.

Programs for Teacher Preparation and Licensure

Nevada Code requires special education teacher candidates complete a transition class for eligibility for state licensure (undergraduate and graduate). However, the state does not recommend or provide guidance as to what content is required for the course. In fact, institutions may choose to combine the transition requirement with another requirement into one class. The following illustrates transition course descriptions at University of Nevada, Las Vegas (UNLV) and University of Nevada, Reno (UNR), the primary special education teacher preparation programs in Nevada.

- **University of Nevada – Las Vegas Transition Courses**
  UNDERGRADUATE - *EDSP 414 Career Education for Students with Disabilities (Crosslisted with EDWF 492A.)* Consideration and design of career education programs for students with disabilities. Transition and adult programs discussed. Prerequisite: EDU 203. 3 credits.

  GRADUATE - *EDSP 734 Vocational and Career Education for Persons with Disabilities in Transition*. Consideration and design of vocational and career education programs for students with disabilities including those with mental retardation, learning disabilities, emotional disturbances, and others. 3 credits

- **University of Nevada – Reno Transition Course Courses**
  UNDERGRADUATE – *EDSP Case Management/Transition in Special Education*. Emphasis on the role of the special education teacher beginning

with a student's referral and identification through their transition into adult living. 3 credits.

GRADUATE – *EDSP 720 Career/Community Life: Persons with Severe Disabilities***.** Theoretical and applied study of adaptive, vocational, career, and community life needs of persons with serve disabilities. Includes community services available for transition planning. 3 credits.

In summary, students with Autism ages 18-21 account for 5% of the participating population in CCSD post-secondary programs which is commensurate with the 5% district-wide incidence of individuals identified with Autism.

Transition Programs by School District

Only one district provided information on transition programs designed specifically for students with disabilities. No districts provided transition programs or services specifically designed for individuals with ASD. Other Nevada school districts either did not offer specific transition programs or did not provide information. However, Elko County School District can provide information for 9 transition students. An overall description of their general autism services is available upon request.

Some regions of the larger districts lack available services for transition. In some cases, it is unclear who has the responsibility for administering transition assessment, developing the transition IEP develop, implementing the IEP, and providing individualized transition services. Many secondary teachers mistakenly believe that these are the responsibility of the transition specialist and, thus, fail to provide students with early preparation for transition to post-school living.

Clark County School District. The Clark County School District (CCSD) provides specialized post-secondary transition programs for individuals with disabilities. Currently, CCSD serves 308 students aged 14-21 with a primary diagnosis of Autism. The majority of these students receive instruction in the general core curriculum while the remaining students are more likely to receive life skills instruction in the specialized classes. Instructional service delivery is based on the IEP.

Fifty (50) students with primary diagnosis of Autism are 18 – 21. Eight of these students participate in one of the following post-secondary programs specifically designed for students with Autism. In summary, CCSD provides services to 16% of students who are old enough to participate in the programs. While this number appears low, it is important to understand that the post-secondary programs are only capable of serving 14% of the total populations of the students with disabilities ages 18-21. In summary, students with Autism ages 18-21 account for 5% of the participating population in CCSD post-secondary programs which is commensurate with the 5% district-wide incidence of individuals identified with Autism.

- **PACE** - Program Approach Career Development
  This is a unique program for post-high school students aims to place students with disabilities into competitive work environments. It provides functional and occupational skills training in building maintenance and culinary arts. Students are linked to various community agencies to promote transition to adult living. The program focuses on the following skills: a) employability skills, b) career exploration, c) job shadowing, d) employment related academics, e) job seeking skills, f) travel training, g) functional academics, h) consumer skills, and i) self-determination.

- **POST -** Postsecondary Opportunities for Students in Transition
  The POST is designed for seniors who will graduate with an Option 2 Diploma. The program emphasizes vocational skills training (e.g., employability skills, career exploration, job shadowing, interpersonal skills, independent skills) and community/life skills training (e.g., community based instruction, travel training, independent living, cooking, career/work experience, leisure and recreation, functional academics). While in the program, students participate in school-based enterprises.

- **YES -**Your Educational Success
  YES is designed to help 11th and 12th grade students with disabilities transition from school to post-secondary educational settings. The program focuses on self-advocacy, the college experience, and study habits. This program is a partnership between CCSD and College of Southern Nevada (CSN). Participants have the opportunity to attend classes at CSN and earn college credit.

- **JDP -** Job Discovery Program
  Students experience a wide variety of work activities. Skill development focuses on a) work-appropriate socialization, b) interpersonal skills, c) task completion, d) self-monitoring, and e) specific work skills. In a 12 month period, students have the opportunity to work in 5 different work sites for 9 weeks per site. This program runs through a joint partnership with Opportunity Village. It was formed to provide an intensive vocational training in a natural work environment for students who require enclave or supported employment options for successful post-school employment.

- **Transition Specialists**
  Transition specialists are employed by CCSD to aid teachers and parents in facilitating the transition from school to post-school services and connecting eligible students with vocational rehabilitation. The lack of expansion

commensurate with district growth and budget cuts has reduced the number of transition specialists to 4-5.

In 2000-2001 school year, there were seven transition specialists and two support staff serving the schools. However, in 2001-2002 SY, CCSD went to the regional model where one transition specialist was assigned to each of the five regions and Helen J Stewart Special School. Helen J. Stewart was also provided a support staff to assist with transition. The seventh transition specialist floated among the postsecondary programs and the other support staff position was left unfilled. Currently, there is one transition specialist at Helen J Stewart and in each region - although one of the positions was unfilled for the majority of this school year - and one part-time transition specialist at the Variety School. The latter is also a Work Experience coordinator. Only one support staff assists a single region in CCSD.

Transition specialists are employed by CCSD to aid teachers and parents in facilitating the transition from school to post-school services and connecting eligible students with vocational rehabilitation. The lack of expansion commensurate with district growth and budget cuts has reduced the number of transition specialists to 4-5.

In 2000-2001 school year, there were seven transition specialists and two support staff.

Community Agencies Providing Education & Transition Services

Several community agencies serve individuals with ASD in transition. The following provides a brief description of larger community agencies and the types of services they provide.

Nevada Parents Encouraging Parents (PEP). Nevada PEP is a federally funded, statewide Parent Training and Information (PTI) Center for Families of Children with Disabilities. The transition coordinator is located at the central office in Las Vegas. The Transition Department focuses on individuals with disabilities between the ages of 14 and 26 who are transitioning into adult life and their families. Key topics are self-advocacy, self-determination, preparing for the world of work and/or post secondary education, and being able to access and make informed choices about work, school, recreation, living skills and community agencies. Three workshops are offered.

- **Helping Our Youth Reach For Tomorrow**
  This workshop reviews the special education rules of IDEA and Nevada's NAC relating to the transition process. Making the transition from the structure of high school to the challenges and responsibilities of adulthood can be a daunting task for many students with disabilities. This workshop gives parents and students information on transition, by using the guide "Where Am I Going? How Will I Get There?" Reviewing the rules and regulations, participants will learn to develop a transition plan that can involve other agencies. Both students and parents will find this training helpful as students move towards college, employment, and living independently.

- **You Can Do It!**
  The "You Can Do It!" presentation will help families and high school students with disabilities prepare for a successful transition into college. Participants receive their very own "You Can Do It" guide which provides strategies and ideas that will help them and their parents prepare for going to college.

- **Solving the Employment Puzzle**
  Parents and youth will be introduced to practical job development strategies and awareness of a wide range of resources that can help youth with disabilities prepare for work, find a job, and stay employed.

Easter Seals – McComb Transition Connect Program. This program serves high school students with special needs to determine their path for the future whether it is full or part time work, volunteer work or post-secondary education. Five transition coordinators partner with the Bureau of Vocational Rehabilitation (VR) and visit all Las Vegas high schools. A team approach is used to determine the best option for the student. Once students have decided to pursue employment, coordinators under the guidance of VR counselors can provide services which include, career exploration, resume preparation, interview skills, job searching, bus training, help obtaining work cards and proper work attire. Internet research is also available. Currently, five youths with ASD are being served by this program.

Partners for Autonomy in Life Skills (PALS). PALS is currently working on employment skills with one individual with ASD. He is 23 years old and has been without a job for over a year. They began getting him ready for employment with a focus on community inclusion and volunteer work geared towards structuring an appropriate daily routine for him. Currently, he volunteers independently for two hours per week and with a shadow (e.g., support staff) for one additional hour. He also participates in shadowed community outings for two hours per week. He has participated in two job interviews arranged through his job developer. The last of the two interviews were recent and seems to be promising for job placement. Once he has an official job placement, PALS will serve as his job coach. Initially, they will serve as a full time shadow, assisting in developing a routine in the workplace and understanding the workplace culture. Over time, they will fade support (pending on his progress) until he is fully independent. Lastly, they will frequently check on his progress to see if he has any needs, concerns, or questions in order to help him to continue to work independently.

PALS also works with three other individuals with ASD ages 17-19. These individuals receive services through the following PALS 1:1 support and group programs.

- **Transition Services**

  PALS works on transition throughout varying stages in life; kindergarten to elementary school, elementary school to middle school, middle school to high school, high school to college or adult life, home school to public school, from old schools to new schools, into workplaces, etc. In regards to transitions from high school to college or adult life, we currently work with four young adults. Two of these young adults (17 yr old Female, 19 yr old male) attend weekly social skills group that has a mix of individuals with ASD from 14-19 years old. The other two young adults work in a 1:1 setting (one individual was mentioned above 23 yr old male, and the other is an 18 yr old male).

  In the group setting, PALS discusses transition in a lecture and practice type model with the focus of the group on social/life skills necessary for independence in adulthood. They discuss conversation skills (greetings, active listening, self advocacy, etc.), recreational skills (game/play skills, active participation, team work, good sportsmanship), and problem solving (using SOCCS: Situation, Options, Consequence, Choice, Strategy).

  In 1:1 settings, there is flexibility in the approach used. The focus depends on the needs and goals of the individual (according to family, individual and our own assessment). For instance, one individual's focus may be on transitioning the individual from an inconsistent routine to a consistently routine schedule. Another focus may be on developing an understanding and preparation for changes that will occur during a transition from high school to college.

- **Community Inclusion Services**

  PALS presents community inclusion in the same way they present transition supports services. They work with groups as well as individuals. The group setting is presented in the same way; however, the 1:1 support focus is different and geared more towards community inclusion.

  Community inclusion goals for 1:1 support are focused on enriching experiences within the community and learning to utilize resources within the community. For instance, the focus can be with utilizing banking services, making purchases appropriately, or developing a budget.

Current Barriers and Recommendations for Individuals with ASD in Transition

Transition Barrier 1: Data Collection

There is a significant problem in capturing the information on the number of students in the transition process served by school districts. Although school districts are required to collect data on students under the primary category of autism, we suspect that the numbers do not reflect the actual number of students with ASD. Autism may be marked as a secondary disability or not at all. Students with Asperger's may not even be identified or may be misidentified. Many students with ASD may have one of the other disability categories checked on their IEP. Other disability categories being used, include, developmental delay (up to age 6), learning disability, speech and language, emotional or multiple. Students with Asperger's may be in regular education with accommodations. Therefore, the numbers students with ASD may be far greater than reported. It is important that students with ASD are correctly identified and subsequently receive an education that will meet their needs and be successful to the best of their abilities. In addition, accurate data is needed to determine the adequacy of current services and make recommendations for future services.

The numbers students with ASD may be far greater than reported.

Recommendations:

1. Nevada will develop a comprehensive statewide system to accurately identify the number of individuals with autism. The state will establish and maintain a statewide registry of individuals with ASD. Participation should include parents, guardians, and individuals with ASD as they are the primary stakeholders in developing future appropriate statewide services and obtaining funding. Information will be kept confidential and its use be determined by the Nevada Autism Task Force.

Nevada will develop a comprehensive statewide system to accurately identify the number of individuals with autism.

2. Each year, all Nevada school districts will report the number of students with a primary and secondary diagnosis of ASD. The purpose is to obtain an accurate count of the number of school-age individuals with ASD.

3. The Nevada Department of Education (NDE) will collect post-school outcome data through the State Performance Plan's Indicator 14 or comparable data collection method for students with a primary or secondary diagnosis of ASD. Life Tracks, Inc., who currently collects the data for the NDE, will survey a representative sample of individuals with ASD each year. The 2008 State Performance Plan (SPP) data for Indicator 14

only includes students with learning disabilities, mental retardation, and emotional disturbance.

The Nevada Department of Education (NDE) will collect post-school outcome data through the State Performance Plan's Indicator 14 or comparable data collection method for students with a primary or secondary diagnosis of ASD.

4. Designate an independent organization to provide leadership in coordinating autism services statewide. This organization will help develop a web-based, clearinghouse site for ASD services and include information from various theoretical orientations. This organization will also provide an independent annual review of statewide progress on Nevada Autism Task Force recommendations.

Transition Barrier 2: Limited Access to School-Based Services

Focus on transition currently is mandated to begin at the age of 14 years old. At this age a student would be moving from middle to high school or would already be in high school. However, beginning the examination of transition at this age may not allow for enough time to prepare students for college, the work force, etc. If the transition process is examined at an earlier age (10 years old), then there may be more time to help build the skills necessary for successful transition.

There is a lack of support for participating in extracurricular activities (clubs, sports, etc.), as well as, a lack of transportation to and from such activities. Participation in these activities and organizations may help to build necessary life/social skills (such as following directions, good sportsmanship, working as a team, etc.) which may aid in the transition to high school, college or work.

CCSD Transition Programs

- The topic of transition and specialized post-secondary transition programs, are not often talked about in IEP meetings unless the student is graduating. Due to this late start, students often encounter waiting list to participate in the CCSD programs.
- Knowledge of when to apply for CCSD programs is not always afforded the student/family
- The intent and outcomes of the programs are often not fully communicated.
- There is a lack of follow through with VR or Disability Resource Center (DRC) once a student ages out
- Lack of individualization in some school based programs.

Recommendations:

Fund additional transition specialists to assist school personnel in connecting all students with disabilities to community agencies and post-school opportunities.

1. Futures planning for each student beginning at age 14 (although earlier is preferred). The purpose is to identify desired post-school outcomes and develop an action plan to help the students work toward those goals. Futures planning encourages person-centered planning and helps facilitate movement toward a common vision for the future.

2. Clarify roles and responsibilities of teachers and transition specialists in the transition planning. Provide both professional development opportunities for teachers and training for parents to clarify their roles in the transition process.

3. Teacher preparation institutions should collaborate to identify desired outcomes of transition courses in the state. A greater focus should be in preparing teachers in the futures planning and transition planning process.

4. Develop a university training program to prepare transition specialists across the state. Currently, few specialists are available to bridge the gap between school and community-based services. A possible funding source includes federal personal preparation grants.

5. Fund additional transition specialists to assist school personnel in connecting all students with disabilities to community agencies and post-school opportunities.

6. Increase the capacity of the current local education agency (e.g., district) transition and post-school programs to provide services to students with more significant disabilities.

7. Create a transition resource guide that is distributed through schools and community agencies to parents/ individuals with ASD beginning at age 14.

8. Restructure the State of Nevada Transition IEP document to facilitate person-centered planning. The students' post-secondary goals should guide the planning process, including selecting appropriate transition assessments, developing an action plan, and creating annual goals. To assist implementing the transition IEP, the document should identify necessary steps and the person responsible, which may include parents, students, community service providers, local education agencies, and teachers.

Increase the capacity of the current local education agency (e.g., district) transition and post-school programs to provide services to students with more significant disabilities.

9. Establish a protocol for providing social skills and life skills training for students with ASD without regard to educational placement. Opportunities should be provided during school, in after-school programs, and in summer programs. Students should learn and practice skills in the most integrated settings possible. The goal is to prepare students to live, work and recreate in their community.

10. High school students with ASD, including students pursuing a standard diploma, will have work experiences in multiple settings commensurate with their abilities prior to exiting school. Work opportunities will explore interests, determine strengths and identify areas of need and support. Opportunities during school, after school and/or school vacations should be available.

11. Mandate that teachers, support staff (including principals), and transition specialists receive education and training on the needs and supports for students with ASD. Provide access to autism specialists as mentors, classroom consultants and teacher support group leaders.

Transition Barrier 3: Preparedness for Post Secondary Education

An increase in the number of students with ASD and early intervention services has correspondingly resulted in an increased interest in attending colleges and universities. Postsecondary education and training are recognized assets in obtaining employment and establishing a career track. Students with Asperger's Syndrome (AS) are often encouraged to attend post secondary schools due to their high academic achievement. However, inadequate preparation during transition can prohibit student success in post school education settings, such as

- A lack of preparation at the middle and high school level to develop the skills needed to navigate the college environment, including self-advocacy, organizational tools, and social skills.

- Failure to address self-help and independent living skills needed to live away from home for the first time (e.g., dorm living, living with roommates).

- Lack of attention to the development of self-determination skills needed to seek assistance with coursework when challenges are first recognized.

- Development of poor social skills and lack of support to correct social errors.

- Failure to inform or connect students with the school disability resource centers.

- Lack of understanding about needs of individuals with ASD among disability resource center personnel.

- Lack of adequate academic and social supports available to students interested in post-school education.

An increase in the number of students with ASD and early intervention services has correspondingly resulted in an increased interest in attending colleges and universities. Postsecondary education and training are recognized assets in obtaining employment and establishing a career track. Students with Asperger's Syndrome (AS) are often encouraged to attend post secondary schools due to their high academic achievement. However, inadequate preparation during transition can prohibit student success in post school education settings.

Recommendations:

12. Provide exposure to transition-age youth with ASD and their parents to Post Secondary Education (PSE) environments and options, including life enrichment programs, campus recreation, activities, events, and clubs. Exposure will include training in "entitlement" vs. "eligibility" reflected in changing from a nurturing education system to those requiring self-advocacy skills.

13. Equip Institutions of Higher Education (IHE) with the tools and resources (e.g., training, financial assistance) to assist individuals with ASD in developing routines, socializing, and adapting to college life.

14. High school guidance and vocational rehabilitation counselors will provide all students with ASD and their parents information about post-secondary education requirements, opportunities and supports by age 16. Information can be presented in collaboration with the IEP team.

15. Provide students with instruction to develop self-determination skills, including goal setting, self-awareness, choice making, self-advocacy, self-regulation, and problem solving. In a post-secondary education environment, for example, the student with ASD will decide when to inform the instructor about his/her disability, if they choose to at all. The New England Asperger's Association suggests that "early disclosure to appropriate college personnel improves the chances for success, and minimizes the chances of misunderstandings or unfortunate incidents…We highly recommend that you give college information about yourself and about AS after you are admitted and before the first semester" (Jekel & Loo, 2003).

References

Autism Society of Delaware. (2005). *Best practices for serving adults with autism: Results of the study on services and supports for adults on the autism spectrum across the United States*. Wilmington, DE: Autism Society of Delaware.

Alwell, M. & Cobb, B. (2006). A map of the intervention literature in secondary special education transition. *Career Development for Exceptional Individuals, 29*, 3-27.

Barnhill, G. P. (2007). Outcomes in adults with asperger syndrome. *Focus on Autism and other Developmental Disabilities, 22*, 116-126.

Blalock, G., Kochhar-Bryant, C. A., Test, D. W., Kohler, P., White, W., Lehman, J., Bassett, D., & Patton, J. (2003). The need for comprehensive personnel preparation in transition and career development: A position statement of the Division on Career Development and Transition, the Council for Exceptional Children. *Career Development for Exceptional Individuals, 26*, 207-226. Retrieved March 12, 2008 from: http://www.dcdt.org/pdf/PersonnelPrepPosition.pdf

Ellerd, D. A., Morgan, R. L., & Salzberg, C. L. (2006). Correspondence between video CD-ROM and community based job preferences for individuals with developmental disabilities. *Education and Training in Developmental Disabilities, 41*, 81-90.

Gerhardt, P. F. (2007, April). Effective transition planning for learners with ASD. EP Magazine, 26-27. Retrieved March 12, 2008 from: http://www.eparent.com/

Grandin, T., & Duffy, K. (2004). *Developing talents: Careers for individuals with Asperger syndrome and high-functioning autism.* Shawnee Mission, KS: Autism Asperger Publishing Company.

Hagner, D. & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism and other Developmental Disabilities, 20*, 91-97.

Jekel D. & Loo, S. (2003). Some useful educational interventions for students with asperger syndrome. Retrieved June 30, 2008 from: http://www.aane.org/asperger_resources/articles/education/educational_interventions_asperger.html

Keel, J. H., Mesibov, G. B., & Woods, A. V. (1997). TEACCH-Supported employment program. *Journal of Autism and Developmental Disorders, 27,* 3-9.

National Autistic Society. Transition planning at the age of 14 (England and Wales). Retrieved March 12, 2008 from: http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1067&a=4412

Reis, S., Neu, T., McGuire, J. M. (1997). Case studies of high-ability students with learning disabilities who have achieved. *Exceptional Children, 63*, 463-479.

Wehman, P. (1995). Forward. In: M. D. Smith, R. G. Belcher, and P. D. Juhrs, P. D (Eds.), *A guide to successful employment for individuals with autism* (pp. *ix-xi*). Baltimore: Paul H. Brooks Publishing Co.

Wehman, P. (2002). A new era: Revitalizing special education for children and their families. *Focus on Autism and other Developmental Disabilities, 17*, 194-197.

Williams, J. M. & O'Leary, E. (2001). What we've learned and where we go from here. *Career Development for Exceptional Individuals, 24,* 51-71.

Winter-Messiers, M. A., Herr, C. M., Wood, C. E., Brooks, A. P., Gates, M. A. M., Houston, T. L., & Tingstad, K. I. (2007). How far can Brian ride the Daylight 4449 Express: A strength-based model of asperger syndrome based on special interest areas. *Focus on Autism and other Developmental Disabilities, 22*, 67-79.

APPENDIX H

Programs Serving Individuals with ASD

Programs Serving Individuals with ASD

Exceptional Programs Serving Individuals with ASD.

1. Autism Services Center, Huntington, WV
2. Bittersweet Farms, Whitehouse OH
3. Chimes Delaware, Newark, DE
4. Community Services for Autistic Adults and Children (CSAAC), Montgomery Village, MD
5. Institute for Applied Behavior Analysis (IABA), Los Angeles, CA
6. Jay Nolan Center, Mission Hills, CA
7. Judevine Center for Autism, St. Louis, MO
8. Division TEACCH (Supported Employment Program), Chapel Hill, NC

Additional Programs

1. ARC of Arapahoe & Douglas County, Centennial, CO.
2. Ask Me! Survey Project, Annapolis, MD
3. Bancroft NeuroHealth, Haddonfield, NJ
4. University of South Dakota, Center for Disabilities, Sioux Falls, SD
5. Dept. of Disability & Special Needs, Autism Division, Columbia, SC
6. Devereux, Santa Barbara, CA
7. Eden Family Services, Bonita Springs, FL
8. Grafton, Winchester, Berryville, and Richmond, VA
9. The Homestead, Pleasant Hill, IA
10. JFK Partners, Denver, CO
11. Linwood Center, Ellicott City, MD
12. NJ Center for Outreach and Services to the Autism Community (COSAC), Ewing, NJ
13. Rusty's Morning Ranch, Cornville, AZ
14. The Sean Ashley House, Houston, TX
15. Center on Disability and Community Inclusion, University of Vermont, Burlington, VT

APPENDIX I

Transition Resources for Individuals with ASD

Transition Resources for Individuals with ASD

- Life Skills for Vocational Success- http://www.workshopsinc.com/manual/ Includes detailed lesson plans on a variety of social and life skills. This site can be used for vocational, social and life skill programming.

  .

- The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations by: Brenda Smith Myles, Melissa L. Trautman, Ronda L. Schelvan. The book provides strategies for teaching social skills, problem solving, feelings, etc.

- Buying with Sense by: Carol L. King. Useful book for teaching money management and basic banking-

- Article from In Business Las Vegas describing the success of a young adult with ASD- http://www.inbusinesslasvegas.com/2006/11/10/healthcare.html

- http://www.myfuture.com/ - This site provides various tools for life after high school. It has tools for learning to manage money, find information about a career, career interest inventory, and other options beyond high school-

Self-Determination Resources:

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum by Ruth Elaine Joyner Hane, Kassiane Sibley, Stephen M. Shore, Roger Meyer, Phil Schwarz, and Liane Holliday Willey.

The 411 on Disability Disclosure: a Workbook for Youth with Disabilities by the Office of Disability Employment Policy and the National Collaborative on Workforce and Disability, can be purchased or downloaded at http://www.transcen.org/.

Sample of useful college supports listed in the 32nd Institute on Rehabilitation Issues (IRI), and published a resource titled, *Rehabilitation of Individuals with Autism Spectrum Disorders* (Dew & Alan, 2007).

- Access to assistive technology, especially in relation to learning needs and or planning, organization, and scheduling
- A reduced course load, at least for the first semester
- A single dorm room
- A social mentor
- An assigned point person to serve as liaison with the student

- Support for executive functioning needs, such as regular check-ins or helping with prioritizing
- Counseling, especially related to social issues that can be quite baffling since there are many new situations, including dating, drinking, and parties

Social situations can be especially challenging for students with ASD so finding a special interest or support group can be helpful. Website information and online supports specific to AS may be a resource to some students. The following information is listed in *Rehabilitation of Individuals with Autism Spectrum Disorders* (Dew & Alan, 2007).

Books and Articles Especially for College Students with ASD with Advice from Peers

One useful website is that of University Students with Autism and AS (http://www.users. dircon.co.uk/~cns/). Another university offers an e-booklet of advice for students with Asperger's called *Towards Success in Tertiary Study with Asperger's Syndrome and Other Autistic Spectrum Disorders,* available at http://www.services.unimelb.edu.au/ellp/publications/ towards.html.

An article called "The Hindered Path" was originally written by Laura Tiffany for the student newspaper at Memorial University. It describes the postsecondary experience for individuals on the autism spectrum. It can be found at http://www.users.dircon.co.uk/~cns/article.html.

Lars Perner, Ph.D., wrote "Preparing to Be Nerdy Where Nerdy Can Be Cool: College Planning for the High Functioning Student with Autism" found at http://www.professorsadvice.com/. This same website has a reprint of an article from the 2003 issue of *Autism-Asperger's Digest* on selecting a college for a person on the autistic spectrum (see http://www.larsperner.com/autism/ colleges.htm). It includes specific details about services offered and contact persons for specific colleges.

In 2004, *Succeeding in College with Asperger Syndrome: A Student Guide* made its debut. John Harpur, Maria Lawlor, and Michael Fitzgerald state that their primary purpose for the book is to "assist those with AS cope with the challenges life brings" and add that the book is also helpful for parents, counselors in student services, and therapists. Another current recommendation for students on the spectrum thinking about college is *Aquamarine Blue 5: Personal Stories of College Students with Autism* edited by Dawn Prince-Hughes (Swallow Press, 2002).

Employment Outcomes for Individuals with ASD

It is evident from discussions with parents, experts in the field of autism, and outcome data that many adults with Autism Spectrum Disorder (ASD) are unemployed or under-employed, including the highest functioning and best-educated individuals.

Brenda Smith Miles, a professor at the University of Kansas, stated "even though autism covers a range of intellectual abilities, few young people with autism find meaningful work (Newsday, 2007)". She found that only six percent of individuals with so-called classic autism are employed. It is evident from discussions with parents, experts in the field of autism, and outcome data that many adults with Autism Spectrum Disorder (ASD) are unemployed or under-employed, including the highest functioning and best-educated individuals.

Individuals with ASD experience a number of personal challenges that make it more difficult to find and sustain meaningful employment. These challenges include behaviors that may present barriers to employment for persons with ASD. Understanding these personal challenges is the first step in improving employment services for individuals with ASD.

The following personal challenges and recommendations are quoted directly from Chapter 5 of a recent monograph entitled *Rehabilitation of Individuals with Autism Spectrum Disorders* (Hundley & Sullivan, 2007). Although the document targets vocational rehabilitation (VR), understanding these personal challenges will assist Nevada State policy makers, community members, and employment agencies in improving employment services for individuals with ASD.

Rehabilitation of Individuals with Autism Spectrum Disorders
(Hundley & Sullivan, 2007).

Challenge 1

Persons with ASD may be nonverbal or not able to answer the VR counselor's questions during the intake process. For example, in some states, the VR counselor is instructed to ask two questions: How do you think we can help you? and How does your disability make it hard for you to work? (Texas Department of Assistive and Rehabilitative Services, 2005).

Recommendations

During the intake process, have a facilitator present who knows the applicant. This person must be someone that the applicant feels comfortable with and someone the applicant wants involved in the intake process. If the applicant is nonverbal or cannot answer a question,

rephrase the question or allow the facilitator to answer. Determine if the person with ASD has a legal guardian and include the guardian if possible and/or feasible.

Challenge 2

Persons with ASD may have difficulty understanding and engaging in conversation. They

- May be nonverbal or have problems expressing themselves
- May not respond to verbal requests
- May be echolalic
- May have a restricted repertoire of responses
- May be very literal
- May not ask any questions or may ask too many questions
- May not understand nonverbal cues
- May not make direct eye contact
- May need an extension of evaluation time to determine eligibility
- May need trial work with real work experience before closing the case

Recommendations

Consider the social aspects of different job environments when making a job placement. Discuss with coworkers the characteristics and behaviors of people with ASD. Build in natural supports so the person can have someone to go to if there is a problem or a need for clarification. Communicate information directly and avoid metaphors and idioms, which may be interpreted literally. For example, ask, "How are you today?" rather than "What's up?" Provide consistency of instruction given by the same person if possible. Do not depend on nonverbal cues—such as telling an individual, "Your job is finished," standing up to leave, and expecting the person to follow. The person may need a verbal directive such as "It is time to leave the room and go to the second workstation; follow me, please." For the nonverbal person with ASD, use a communication aid such as a picture cue system or some form of assistive device that aids the person with communication. People with ASD often require extra time to process conversation.

Any time a request is made, wait for a response before repeating the statement. Don't ask a series of questions. Tell the person, using clear, concise, concrete language, what you want him to do. Model the appropriate behavior. Structure, order, routine, and clear rules and assignments are the key to success for a person with ASD (Hurlbutt & Chalmers, 2004; Doyle, 2003).

Challenge 3

Persons with ASD may have difficulty with problem-solving and drawing inferences. They

- May not be able to "read between the lines"
- May appear regimented and have one way of performing a task
- May have unpredictable responses to a change in routine or situation

- May deal with a situation in a concrete manner
- May have difficulty transitioning from one situation to another situation

Recommendations

Secure a job that requires limited problem-solving skills. Provide a job task which, once started, can be finished without interruptions. One example is an assembly job that requires the same steps every time it is performed.

When teaching the job, have the person with ASD restate the directions. Break directions down into simple steps, with time limits delineated for completion of a task. Provide a consistent work station or work set-up. Ensure that the employee knows what to do when the task is finished. Provide regular reminders and positive feedback.

Develop a system for transitioning from one task to another. Be sure that during a break or downtime, the person with ASD has a preferred activity to engage in, such as a video game.

Challenge 4

Persons with ASD may be rigid in their thinking and assume that other people think the same as they do. They

- May have problems with authority figures and may not understand hierarchy
- May be egocentric and have trouble reading other people's behavior in relation to theirs (which is known as theory of mind deficit)
- May organize their world differently (locate their office by some particular object or item rather than an office number)
- May have tunnel focus or concentrate on just one thing and be unable to pay attention to other important details (Shattuck, 2001)

Recommendations

State differences of opinion calmly and in a nonconfrontational manner. Avoid suggestive and indirect language (Myles & Simpson, 2003).

Provide training to coworkers and supervisors in how best to solve a problem. Explain the situation in terms of the problem and not the person (Shattuck, 2001). Attempt to emphasize the concrete aspects of the task, not the big picture. Teach the job right the first time by establishing a routine as quickly as possible. For example, use a pictorial chart of the hierarchy of who to go to if there is a problem (Emmett, 2004).

Challenge 5

Persons with ASD tends to learn social skills without learning their meaning or context (Myles & Simpson, 2003). They

- May lack awareness of the unwritten rules of social conduct
- May not understand the concept of making small talk (for example, asking a coworker how his weekend was or how he

enjoyed a movie)
- May not appreciate the feelings and thoughts of others
- May not realize that a comment would embarrass or cause offense to another person and that a simple apology could help repair the person's feelings (Attwood, 1998)
- May lack emotion or may not use spontaneous gestures, touch, or facial expressions
- May misunderstand humor and sarcasm
- May appear rude and unfriendly (Seltzer & Krauss, 2002)

Recommendations

Social skills that are needed on the job must be trained, just as technical skills are trained. Social skills are critical for successful employment. Two methods for teaching appropriate social skills are role playing and video modeling. All of the references listed in this chapter are excellent resources for teaching social skills.

Discuss with coworkers the individual's response to certain situations, such as lack of eye contact, failure to make small talk, or walking between two people who are talking. Others may perceive these responses as rudeness. However, they should be explained as a common characteristic of autism. Job coaches and other staff must be very consistent in the way they teach the person social behavior necessary for successful employment.

Challenge 6

Persons with ASD may have unusual responses to tactile, olfactory, auditory, and visual stimuli, which may cause difficulty in the work environment. They

- May be distracted or disturbed by different types of sounds, lighting, and smells (Grandin & Duffy, 2004)
- May be negatively impacted by the environmental clutter of a job site

Recommendations

Respect the sensory sensitivities by designing the work area to minimize seriously distracting sights and sounds. For example, allow the individual to wear ear plugs or to listen to his or her choice of music through headphones; use tinted glasses to minimize the effect of fluorescent lighting or other harsh light; have the employee's work station near a window that provides natural light; and if the employee is required to wear a uniform, allow modifications that will make the uniform more comfortable.

A useful technique for self-regulation could include relaxation and deep breathing exercises. Schedule sensory breaks throughout the work day to assist the employee in coping with the busy work environment.

Be sure that the solution to the person's sensitivities is not degrading and does not call undue attention to the problem. Do not sneak up on someone with ASD or startle them. If the person's back is turned, announce yourself. If the person gets too close to you when talking,

calmly ask the person to move back a step. A quiet setting out of heavily trafficked areas is usually the best work location for someone with ASD (Grandin & Duffy, 2004). If clutter is a problem, develop a plan (and share it with the person with ASD) to get things organized into neat specific categories. People with ASD are "systemizers," which could be a real asset on a job.

Challenge 7

Persons with ASD may have impaired fine or gross motor skills accompanied by complex body mannerisms. They

- May have compulsions and/or rituals, such as opening a door at a certain angle every time
- May have circumscribed interests and are extremely rigid in their thinking (Seltzer & Krauss, 2002)
- May be clumsy, have problems with pencil grasp, and write illegibly
- May need positive motivation to work—even for the many ASD employees who are well coordinated, with excellent fine and gross motor skills

Recommendations

Carefully match the job with the individual's interests and skills. Analyze the job and make adaptations using jigs and other prostheses that can help compensate for deficits in fine and gross motor skills. Consult with an occupational therapist who could assist in making accommodations for the individual (Myles & Simpson, 2003).

Build on the compulsions and rituals of the person whenever possible. For example, a person who memorizes the rules of grammar will probably do well in a job requiring coding and classifying books or materials.

Challenge 8

People with ASD typically do not interview well for a job. They

- May not answer the question posed
- May go off on a tangent
- May not maintain eye contact with the interviewer
- May give unrelated answers to questions

Recommendations

Facilitate the interview process with the applicant through role playing. Highlight the applicant's strengths. Have a resume prepared. Practice rote responses and have four or five questions prepared for the interviewer. Assist the person with ASD in planning for and dressing appropriately for the job being sought. If it is a mechanic's job, a suit and tie would not be appropriate (Grandin & Duffy, 2004); however, the person with ASD will not know what is and what is not appropriate dress. In lieu of the traditional job interview, an arrangement could be made for the employer to make available short-term job try-outs, in order to demonstrate the person's abilities and strengths (Hagner, 2005). Three or four different on-the-job try-outs could be helpful in assessing desires and capabilities. A well-trained job coach will make

sure that the employer perceives the person with ASD as an asset and helps to ensure that the job will be done as the employer expects.

Challenge 9

Persons with ASD may engage in challenging behaviors:

- Stereotypical behavior such as arm flapping, rocking, or odd verbal noises
- Social peculiarities, social interaction difficulties, and to a lesser degree, aggression and anger (Myles & Simpson, 2003)
- Narrow set of interests

Recommendations

If possible, procure a job with duties that enable the person's challenging behavior to become an asset. For example, an individual who likes to break glass could work in a glass recycling job which requires the employee to toss glass items into a large bin. A person with ASD whose intense interest is putting together a 500-piece jigsaw puzzle would probably be successful in an intricate assembly job. The employer and coworkers must feel confident that if a behavior problem occurs, the job coach or supporting agency will effectively and efficiently handle the situation with a minimum of worksite disruption. The job coach must systematically identify the problem and then design and implement a solution. Personal networking and the development of ongoing relationships with employers must be maintained. If the person is presently taking medication to assist in controlling anxiety, depression, or any other comorbid condition, make sure assessments are made on a regular basis to ensure that he or she is taking the medications properly.

Challenge 10

Persons with ASD may not respond well to change that may occur on the job. They

- May not generalize skills from one place to another
- May not multitask

Recommendations

When training a new set of job skills, keep the conditions consistent until the employee is responding correctly on a regular basis. Then gradually fade the instructions and prompts as the employee begins to acquire the skill (Scheuermann & Webber, 2002).

Provide support during transition from one task to another. Doing one task at a time is more suitable for the person with ASD (Grandin & Duffy, 2004).

Scheduled job duties need to follow a predictable pattern. Transitions need to be carefully planned and carried out gradually. When change/exceptions must occur, give the employee with ASD as much notice as possible and explain the change. For example, his desk must be moved. If possible, give him choices in some aspect of the move, like which way his desk faces in its new place. Facilitate generalization of skills by briefly retraining the task in the new work environment (Emmett, 2004).

References

Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals.* London: Jessica Kingsley Publishers.

Doyle, B. T. (2003). *Personal style and interactions for working with individuals affected by autism spectrum disorder.* Seattle, WA: New Horizons for Learning. Retrieved September 7, 2006, from http://www.newhorizons.org/spneeds/autism/ doyle_communication.htm

Emmett, J. (2004, March 16). *Employment for individuals with autism spectrum disorders* [teleconference]. Champaign, IL: RSA Region V CRP-RCEP. Retrieved September 7,

2006, from http://www.ed.uiuc.edu/illinoisrcep/activities/archivedteleconferences.htm

Grandin, T., & Duffy, K. (2004). *Developing talents: Careers for individuals with Asperger syndrome and high-functioning autism.* Shawnee Mission, KS: Autism Asperger Publishing Company.

Hagner, D. (2005, December 28). *Developing business capacity to include employees with autism.* Durham, NH: Institute on Disability at University of New Hampshire. Retrieved September 7, 2006, from http:/iod.unh.edu/projects/dev_business_capacity.html

Hurlbutt, K., & Chalmers, L. (2004). Employment and adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 19*(4), 215-222.

Myles, B. S., & Simpson, R. L. (2003). *Asperger's syndrome: A guide for educators and parents.* Austin, TX: Pro-Ed.

Scheuermann, B., & Webber, J. (2002). *Autism: Teaching does make a difference.* Belmont, CA: Thomson Learning.

Seltzer, M. M., & Krauss, M. W. (2002). *Adolescents and adults with autism: A study of family caregiving.* Madison, WI: Lifespan Family Research, University of Wisconsin- Madison.

Shattuck, P. (2001, January). Initial findings from the Waisman Center's landmark study. *The Spectrum.* Retrieved September 7, 2006, from http://www.asw4autism.org/Madison/ jan01.htm

Texas Department of Assistive and Rehabilitative Services. (2005, August). *A guide for applicants.* Austin, TX: Author. Retrieved September 7, 2006, from http://www.dars.state.tx.us/drs/VRguide_english.pdf

Current Practices and Data in Nevada for Individuals with ASD Seeking Employment

Until recently, vocational rehabilitation (VR) agencies rarely provided services to individuals with autism and/or Autism Spectrum Disorder.

Until recently, vocational rehabilitation (VR) agencies rarely provided services to individuals with autism and/or autism spectrum disorder (ASD) (Dew & Alan, 2007). However, VR offers supported employment which has been identified as a potentially successful strategy in assisting individuals with ASD to achieve employment outcomes. The primary service in supported employment is job coaching, which is provided by a job coach. A job coach is a person at the job site who role is to help an individual with a severe disability learn and perform a job. In addition to teaching specific job skills, the job coach is responsible for teaching the "soft skills" needed for success in the workplace (e.g., appropriate behavior, timeliness, personal hygiene, respect for coworkers and supervisors, and appropriate communication).

Once the individual has successfully transitioned to his or her new position, the job coach is expected to fade his or her support which will allow the individual to exit the VR system and enter into extended services. The lack of extended services, also called long-term support, has been identified as one of the major barriers to the successful employment of persons with ASD. "Funding cuts to state developmental disabilities agencies as well as the reduction in Medicaid waivers has restricted the ability of VR agencies to utilize supported employment (Dew & Alan, p. x).

For the purpose of this document, the definition of services found in the VR federal regulations is utilized:

- **Supported Employment** means:
  Competitive employment in an integrated setting, or employment in integrated work settings in which individuals are working toward competitive employment, consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals with ongoing support services for individuals with the most significant disabilities—
  (A) For whom competitive employment has not traditionally occurred or for whom competitive employment has been interrupted or intermittent as a result of a significant disability; and
  (B) Who, because of the nature and severity of their disabilities, need intensive supported employment services from the designated State unit and extended services after transition as described in paragraph (b)(20) of this section to perform this work. [34 CFR 361.59(b)(53)]

- **Extended services** are defined as:

  (20) Extended services means ongoing support services and other appropriate services that are needed to support and maintain an individual with a most significant disability in supported employment and that are provided by a State agency, a private nonprofit organization, employer, or any other appropriate resource, from funds other than funds received under this part and 34 CFR part 363 after an individual with a most significant disability has made the transition from support provided by the designated State unit. [34 CFR 361.5(b)(20)]

Vocational rehabilitation pays job developers to identify and help potential clients gain access to meaningful employment. These individuals are the primary method of finding employment for individuals eligible for vocational rehabilitation services.

Rehabilitation Automated Information of Nevada (RAISON) is currently using a four digit disability code to track individuals utilizing VR services. The first two digits track impairments (none, sensory/communicative, physical, mental) and the second two digits track the primary cause of the impairment (autism is 08 of 37 categories). Data between 1/1/05 and 12/31/07 shows there were 46 individuals with autism served. The actual numbers may be higher since the autism code must be selected as the primary disability. Individuals with ASD could fall under other categories and therefore not counted under the autism category. Of the 46 individuals with autism, 9 were employed, 15 with services pending and 22 cases closed. The statewide distribution of individuals includes 8 from northern and rural Nevada and 38 from the southern district (Dr. Michael Coleman, personal communication 2008).

Vocational rehabilitation pays job developers to identify and help potential clients gain access to meaningful employment. These individuals are the primary method of finding employment for individuals eligible for vocational rehabilitation services. Currently, these individuals are paid around $2000 dollars for each client who is placed and maintains the job for a certain period of time (90 days). The job developer is paid in increments based on the individual's status in finding a job. For example, they get paid around $100 for intake, and then some of assessment, and then based on the length of success in the position (30, 60, and 90 days). This service may be under utilized for individuals with ASD.

The ideal post school employment outcome should be inclusive, competitive employment.

The ideal post school employment outcome should be inclusive, competitive employment. However, other job opportunities – center-based work environments, work centers, work crews, and enclaves – may be obtained through privately funded agencies and independent employment searches.

Barriers and Recommendations for Individuals with ASD Seeking Employment

Data on individuals with ASD who are seeking employment or are employed is limited to nonexistent.

Employment Barrier 1:

Data on individuals with ASD who are seeking employment or are employed is limited to nonexistent. Current data does not provide information to improve employment outcomes for individuals with ASD. Specifically, data are needed to determine the extent to which individuals with ASD seek and obtain employment from disability-based employment services and agencies, including vocational rehabilitation and private organizations. Specifically, information about who applies, who is eligible and not eligible, and who receives what services would assist in improving services and identifying gaps in current services. In addition, the collection of data regarding characteristics of services provided and employment status of individuals receiving those services – length of job search, location of employment, type and nature of employment, and time between employment – would also aid in identifying gaps in services and improve current services.

Recommendation:

1. **Using a standardized data collection tool, collect employment data – such as length of job search, time between employments, and locations of employment outcomes (e.g., center-based workshops, enclaves, competitive jobs) – from disability-based employment agencies (i.e., vocational rehabilitation, private agencies, and non-profit organizations) about the employment services sought and obtained by individuals with ASD.**

Employment Barrier 2:

There is a lack of understanding on the employability of individuals with ASD. Employers and employment services are unaware of the benefits of hiring individuals with ASD. Subsequently, there is lack of employment opportunities in the community, especially in competitive jobs, for individuals with ASD.

Recommendations:

2. **Employment agencies and services (e.g., vocational rehabilitation, private organizations) will promote successful employment outcomes for individuals with ASD and share information with potential employers.**

3. **Develop a promotional campaign aimed at educating businesses on the benefits of employing people with disabilities (e.g., brochure, radio announcements, television broadcasts). The outcomes are to increase**

awareness among potential employers and increase the job bank.

4. **Provide employment agencies and services with a networking tool designed to increase access to and relationships with employers who can provide volunteer opportunities, work experience, and/or long-term employment.**

Employment Barrier 3:

Current policies and procedures create a disincentive for employment agencies and job developers to spend the extra time and resources needed to assist individuals considered "hard-to-place" in obtaining meaningful employment.

Individuals with ASD with significant behavior and communication challenges often have more difficulty securing long-term employment through disability-based employment services. These individuals, offered referred to as "hard-to-place", may spend years in search of employment, have unsuccessful job experiences, and have longer episodes of unemployment resulting in long periods of unproductive downtime. Current policies and procedures create a disincentive for employment agencies and job developers to spend the extra time and resources needed to assist individuals considered "hard-to-place" in obtaining meaningful employment. Furthermore, there is little to no incentive for employers and employment agencies to invest additional resources and staff training targeted at sustaining long-term employment of individuals considered "hard-to-place."

Recommendation:

5. **Provide monetary incentives to employment agencies and service providers who secure meaningful, long-term employment (90 days or more) for individuals with ASD considered "hard-to-place."**

6. **Provide employment agencies and service providers, prospective employers, and current employers incentives to provide employee training about ASD and developing natural supports (those not requiring paid supports) to improve opportunities for long-term employment.**

Employment Barrier 4:

Individuals are often directed to specific employment niches without regard to abilities and interests thereby decreasing the likelihood of successful outcomes.

Recommendation:

7. **Provide a variety of opportunities for individuals with ASD to obtain work experience in the areas of abilities and interests and use those opportunities to assess job potential. Utilize job-carving strategies to find job niches matching employee and employer needs.**

Employment Barrier 5:

There is a lack of training for all employment related professionals and support staff on the needs and supports required by individuals with ASD. As a result, many individuals with ASD either lack opportunities for employment or have unsuccessful employment experiences leading to job loss.

There is a lack of training for all employment related professionals and support staff on the needs and supports required by individuals with ASD.

Recommendations:

8. **Educate all employment service agencies, including Vocational Rehabilitation and approved contractors, on the Personal Challenges #1 through #9 experienced by individuals with ASD as presented in Chapter 5 of 32nd IRI Rehabilitation of Individuals with Autism Spectrum Disorders.**

9. **Vocational Rehabilitation will provide services from an ASD consultant or create an in-house position responsible for ongoing ASD education to train counselors, staff and potential employers. The committee recommends that Vocational Rehabilitation refer to the recommendations found in this document and Chapter 5 of 32nd IRI Rehabilitation of Individuals with Autism Spectrum Disorders in developing training modules.**

With the rise in the number of cases of Autism, all VR counselors and job trainers will inevitably work with individuals with ASD. Through a collaborative effort, the Rehabilitation Services Administration published the *Rehabilitation of Individuals with Autism Spectrum Disorders* to help prepare VR counselors, job coaches, and job developers for the challenges they may face when working with individuals with ASD. This committee recommends that employment agencies, including vocational rehabilitation, follow the recommendations outlined below. These "systemic challenges are the issues VR counselors may encounter when attempting to adapt the current practices and make these systems work for individuals with ASD" (Dew & Alan, 2007).

The following is directly from the *Rehabilitation of Individuals with Autism Spectrum Disorders* (Hundley & Sullivan, 2007).

Systemic Challenge 1

Few job coaches have the specialized skills required to support persons with autism. Job coaches may not have training on how to support persons with ASD, and untrained job coaches can lose their job while the person with ASD is still employed (Smith, 1990).

Recommendations

VR counselors seeking job coaches should look for these personal attributes:

- Great communication skills
- Intellectual curiosity
- High energy level
- A striving for excellence
- Initiative; being a self-starter
- Respect for the dignity and worth of a person with ASD
- Keen sense of appropriate dress for self and person with ASD, taking into account the culture of the job and community
- Keen sense of grooming and personal hygiene
- Creativity

In addition, VR counselors who find job coaches with these attributes should train them for specific skills:

- General knowledge of characteristics of autism
- Understanding of the "theory of mind" (see Glossary)
- Knowledge of positive behavior supports and how to implement them
- Skill to assess the sensory needs of the person with ASD and to modify the work environment to meet these needs
- Skill to conduct a functional assessment of behavior
- Ability to communicate with the person with ASD
- Ability to support the person with ASD to ensure success on the job
- Ability to use information from a functional assessment of behavior to minimize challenging behavior
- Ability to manage challenging behavior with positive behavior supports
- Ability to coordinate information from a task analysis of the job and needs of the person with ASD to provide the best level of support
- Ability to address employee/employer relations

Job coaches and their supervisors must be knowledgeable regarding the range and type of behavior and challenges faced by the person with ASD in the workplace and must be capable of designing supports that enable success on the job.

Job coaches and their supervisors must be knowledgeable regarding the range and type of behavior and challenges faced by the person with ASD in the workplace and must be capable of designing supports that enable success on the job (Department of Public Welfare, Commonwealth of Pennsylvania, 2004). Job coaches must be trained and have first-hand knowledge of the job. It is important to teach the job skill in the setting where the person with ASD will be working. This should minimize the need to generalize from cues in the training setting to cues in the work setting (Smith, 1990).

A job coach who knows and understands the person with ASD is essential to successful job placement (Autism Society of Delaware, 2005). Experienced and qualified job coach trainers should mentor less experienced job coaches. A career path in job coaching should be encouraged and compensated at a higher level. Perhaps the Association of Community Rehabilitation Education could develop a certification for job coaches. Collaboration with programs such as the Commission on Rehabilitation Counselor Certification to mandate ASD training for certified rehabilitation counselor continuing education hours is

recommended. Staff support ratios must be individualized and may vary from time to time, depending on life and job circumstances. Job coach support should be faded gradually and systematically. In some cases, continual job coach support may be necessary for long periods if the person with ASD is to maintain employment.

Systemic Challenge 2
Few VR counselors have professional training or experience working with persons with ASD. The severe shortage of trained professionals who work with adults with ASD is a significant barrier for training VR counselors.

The lack of funding for long-term support seriously jeopardizes employment for this vulnerable population.

Recommendations

College and university departments who train VR professionals need to provide coursework and practicum experience in ASD. Federal, state, and regional administrators of VR should provide in-service training for all professional staff in their departments to work with persons with ASD.

The Rehabilitation and Continuing Education Program should increase training in ASD… The leadership of VR agencies should conduct in-service training and utilize providers in the community who have experience and expertise working with adults with ASD. Information on existing community providers in the U.S. can be found at the website of the National Association for Residential Providers for Adults with Autism (NARPAA; www.NARPAA.org).

Systemic Challenge 3
VR services are outcome driven and time limited; however, a person with ASD may need lifelong support. Significantly reducing job support may result in job loss for a person with ASD.

Recommendations
The Rehabilitation Services Administration (RSA) should collaborate with other federal agencies to secure funding for the long-term support needed when VR services end. At this time there is no mandate for such a funding arrangement. Medicaid's Home and Community Based Waiver Program will fund job coaches, but that support is not mandatory. The lack of funding for long-term support seriously jeopardizes employment for this vulnerable population. The system needs to provide a seamless continuum of services.

Systemic Challenge 4
Research information on best practices for employment of persons with ASD is very limited. Most of the current research is being conducted with children.

Recommendations
Universities should collaborate with the public and private sector in the autism community for outcome-based applied research on promising practices for successful employment, such as

- The application of technology using video modeling
- Determination of the best job match
- Social skills training for adults
- Job coach training
- Development of natural supports

The system needs to provide a seamless continuum of services.

Systemic Challenge 5
VR counselors' involvement with public schools sometimes does not begin until the person with ASD is about to graduate. Appropriate functional skills for employment may not have been taught.

Recommendations

- A transition plan with the parents/guardian, the individual, the school district, the community disability agency, and the VR counselor should be developed and implemented by age 16 for the person with ASD.
- At age 16 an application for developmental disability long-term funding should be completed and submitted so VR services can start at age 21, or upon leaving school.

Systemic Challenge 6 _
There is a severe shortage of agencies that provide specialized services for adults with autism. Only about 25 agencies in the U.S. provide adult autism-specific services, and most of those agencies are members of NARPAA.

Recommendations
A good choice for a vendor would be an agency that has experience delivering services for adults with autism. For contact information on experienced agencies, go to the www.NARPAA.org website. The Autism Society of America website (www.autism-society.org) is another resource. Websites on autism should include information and links regarding employment of persons with ASD. If autism-specific services are not available in your area, attempt to find a community developmental disability agency that would be willing to be trained in autism. Training should be provided by a specialist in adult autism issues and needs. Use the NARPAA Standards, which are located in Appendix F, for evaluating vendor staff qualifications. Given the shortage of knowledgeable vendors, the VR counselor may need to provide case management for the person with ASD.

Systemic Challenge 7
This IRI document will be widely disseminated by VR agencies, conference presentations, and online links. We need to ensure that it will have a positive and timely impact for persons with ASD.

Recommendations

- Measure the impact on employment for persons with ASD.
- Determine a baseline from the RSA-911 report (See Glossary) for persons with ASD.

- Periodically review the RSA-911 report over the next 5 years to determine the impact.
- Ensure that websites of autism organizations contain links to the IRI document.
- Review this IRI document in 5 years and update it with current information, then redisseminate the information.
- Develop a network of resources of VR counselors and autism providers. Provide meaningful opportunities for the groups to work together.

REFERENCES

Autism Society of Delaware. (2005). *Best practices for serving adults with autism: Results of the study on services and supports for adults on the autism spectrum across the United States.* Wilmington, DE: Autism Society of Delaware.

Department of Public Welfare, Commonwealth of Pennsylvania. (2004, December). Chapter 12: Needs of adults, ages 21 and over. In *Autism Task Force Final Report*. Harrisburg, PA: Office of the Secretary. Retrieved September 7, 2006, from http://www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTask Force

Smith, M. D. (1990). *Autism and life in the community: Successful intervention for behavior change.* Rockville, MD: Brookes Publishing.

References

Dew, D. W., & Alan, G. M. (Eds.). (2007). *Rehabilitation of individuals with autism spectrum disorders* (Institute on Rehabilitation Issues Monograph No. 32). Washington, DC: The George Washington University, Center for Rehabilitation Counseling Research and Education.

Hundley, A. P., & Sullivan, R. C. (2007). Chapter 5: Challenges and recommendations. In D. W. Dew. & G. M. Alan (Eds.), *Rehabilitation of individuals with autism spectrum disorders* (Institute on Rehabilitation Issues Monograph No. 32). Washington, DC: The George Washington University, Center for Rehabilitation Counseling Research and Education.

Newsday. (2007, December 3). *Large number of autistic adults entering the work force*. Las Vegas Review Journal, 14a.

This section will provide the reader an overview on inclusive recreation in Nevada, while focusing on individuals with autism. It is organized by first detailing the benefits of inclusive recreation programs, particularly with including youth with disabilities. The document also includes an overview of inclusive and adaptive recreation in Nevada with descriptions of programs in the north and south, followed by known barriers to community inclusion for individuals with Autism Spectrum Disorder (ASD) and corresponding recommendations to overcome these barriers.

Summary of Best Practices in Community Inclusion for Youth and Young Adults with Autism

Introduction by Barbie Lauver[2]

Positive inclusive recreational experiences help to counter negative stereotypes, promote mutual acceptance, develop friendships, and, thereby, contribute positively to self-development.

Participation in inclusive contexts (e.g., where people with and without disabilities participate alongside each other) is generally associated with beneficial outcomes for youth with and without disabilities (Edwards & Smith, 1989; Sable, 1992; Schleien, Ray, Soderman-Olson & McMahon, 1987, as cited in Wilhite, 1999). Unfortunately, naturally occurring interactions between youths with and without disabilities is usually limited in school (passing each other in the hallway or in the cafeteria, or perhaps working on a special project together) and extra-curricular school activities (where most programs are segregated). This lack of reciprocal interactions can influence the degree of acceptance of youths with disabilities by youths without disabilities, and also discourage youths with disabilities to participate in certain activities for fear of burdening others or being embarrassed. A general consensus among all youths was that acceptance in various environments was important and that they just wanted to fit in. However, research that examined the importance of sport and leisure participation in the lives of youths with and without disabilities revealed that while all youths agreed that participation was beneficial, youths with disabilities placed less emphasis on the importance of participating in these activities than their peers without disabilities. This attitude is believed to be based on their unfavorable past experiences in integrated social activities (Wilhite, Mushett, Goldenberg, & Trader, 1997, as cited in Wilhite, 1999).

2 Barbie Lauver is a parent of child with high functioning autism and the founder of Asperger's Syndrome/High Functioning Autism Support Group.

Leisure appears to be a significant context in which young people develop self-perceptions (Haggard & Williams, 1992; Kelly, 1983; Larson, 1994; Silbereisen & Todt, 1994, as cited in Wilhite, 1999). In order to determine how inclusion influences self-perceptions, Wilhite's team conducted a study to gain insights as to why inclusion works for some youths but not for others, and what were the best methods to support successful inclusive leisure experiences. The participants were middle and high school students with and without disabilities. Most of the youths with disabilities felt that competitive activities were not conducive for achieving acceptance because it could be embarrassing and demeaning. However, inclusive community recreational programs – where attention is focused on the participants' strengths versus weaknesses, where no one is rejected based on ability, and where positive social interactions is encouraged – was found to be important for both youths with and without disabilities. In this regard, "leisure was considered to be an opportunity for bridging some social and physical barriers, as well as emphasizing or creating others" (Wilhite, 1999).

Benefits of Inclusive Recreation Programs

If inclusive recreational programs are to be successful, they must be conducive to the actual participation in the program rather than to winning or losing. Because self-perceptions are created through social interactions with others, recreation environments that provide opportunities for mutually beneficial interactions and relationships enhance communication and influence positive self-perceptions. Positive inclusive recreational experiences help to counter negative stereotypes, promote mutual acceptance, develop friendships, and, thereby, contribute positively to self-development (Wilhite, 1999).

On one hand, youths with disabilities can increase their social skills and develop friendships with other youths in the programs. Also, every positive situation they experience gives them the courage and willingness to attempt new experiences. The self-confidence that they develop carries on into other areas of their lives. On the other hand, youths without disabilities positively integrating with youths with disabilities can cause the youths without disabilities to become more sensitive to individual differences. This awareness and attitude of acceptance will carry on into other areas of their lives, too. They will begin to view people with disabilities as people first and disability second, instead of the other way around.

Inclusive recreation programs can benefit everyone. Most youths with disabilities have experienced limited success in interacting with typical peers due to misunderstanding or intolerance of their differences. However, involvement in a well-planned inclusive recreational program where the staff is trained, behavioral support plans are in place, adaptive equipment is available – all enabling a more equal setting – can become a win-

win situation for both youths with and without disabilities (Wilhite, 1999). Perhaps, someday socially inclusive programs will become the norm rather than the exception.

In the past, young adults with developmental disabilities and significant support needs were provided with recreational, leisure and social activities that were almost exclusively segregated and operated by disability organizations. With the passing of the Americans with Disabilities Act in 1990, which prohibits programs and services from discriminating against persons with disabilities, research on the benefits of inclusive recreational programs has resulted in a tremendous growth of inclusive recreational programs and opportunities (Paiewonsky, 1999). Almost half-a-dozen community inclusion models exist from various cities across the United States where each city provides an overview and positive effects of their particular inclusion programs. "Research has provided clear evidence of the multitude of benefits of inclusive recreation and leisure. Parents have spoken about these benefits in very real terms" (Modell, 1998). Harper and Heal (1993) conducted interviews with individuals with disabilities and found that those who participated more regularly and had greater access to recreation and leisure activities were significantly more satisfied with their lives than their peers who did not (as cited Modell, 1998).

"Research has provided clear evidence of the multitude of benefits of inclusive recreation and leisure. Parents have spoken about these benefits in very real terms"

Some youths with disabilities are hesitant to participate in such programs due to the threat of possible rejection or failure. Therefore, what are the necessary qualities that an inclusive recreation program must possess in order for youths with disabilities to feel welcomed and accommodated? What barriers must be overcome to attain successful integration? In order for inclusion to be successful, both physical and social integration should be considered. Also, the philosophy and attitude that integration is possible for all children is crucial in order to provide the necessary supports for positive inclusive recreational experiences. A team consisting of agencies, professionals, parents and youths must work together to determine how best to encourage participation and interaction and what supports are needed to make this possible. What types of direct or indirect supports should be provided to increase the young adult's participation in activities and their interactions with others? Supports that provide social interactions and friendships (support people modeling appropriate behavior, support people providing a connecting link between youths and then backing off when necessary) along with individualization and flexibility (constant adaptation of the types and levels of supports needed) are key elements in developing positive experiences for all youths) (Walker & Shoultz, n.d.). What considerations must be addressed in order to make the recreation a positive experience for the youth? Most agencies look toward the parents for these answers. "Typically, parents have the most influence on whether or not their children will participate in inclusive recreation and leisure" (Modell, 1998).

> When my son was six years old, he joined a t-ball team. Before the first practice and game, I contacted all of the parents on my son's team and told them that he had high functioning autism. I also provided them with information regarding his social deficits and different behaviors. From the first practice through the last game, the other parents were very supportive in encouraging my son's peers without disabilities to model the desired behaviors, and occasionally adapted the levels of support for my son to successfully handle the many rules of the game. Because of the attitudes, acceptance, and flexibility portrayed by both the parents and his peers, my son had a very positive experience playing t-ball that season. If I had not provided the other parents with any information on autism and how it affected my son's behavior, the experience could have turned out quite differently (Parent of a child with Autism, Nevada).

"Inclusive recreation and leisure can provide innumerable opportunities for youths with and without disabilities to interact and increase their overall quality of life"

In 1997, Scott J. Modell, Ph.D., Professor at Sacramento State, conducted a study to investigate inclusive recreational patterns of children with disabilities through the eyes of their parents. The study revealed five categories of responses that emerged as a result of the survey. Category one is learning from diversity, which develops from the parents wanting their children to participate in a heterogeneous atmosphere – the real world. Society, itself, is inclusive and children should interact with all children regardless of race, religion or disability. Category two is learning from each other, which results from the feeling that inclusive experiences were important for learning and awareness to take place. Category three is communication, which expresses the beliefs that a main benefit of inclusion was that children with and without disabilities were given the opportunity to communicate with each other. Category four is developing socially, which focuses on the importance of disabled children to develop socially appropriate behavior, friendships and social skills. It was felt that in order for children to develop acceptable behaviors, they must be exposed to it. Lastly, category five is the barriers to participation, which are mostly identified by the frustrations experienced with both programmatic (safety, lack of programs) and attitudinal barriers (acceptance and ignorance) (Modell, 1998).

"Inclusive recreation and leisure can provide innumerable opportunities for youths with and without disabilities to interact and increase their overall quality of life" (Modell, 1998). Although, ongoing and informal opportunities of interaction between youths with and without disabilities is crucial for the development of positive attitudes, integration alone does not guarantee successful experiences if a child has a social skills deficit. While most children learn these basic skills simply through exposure to social situations, children with ASD need explicit instruction provided by trained personnel followed by reinforcement through a more structured environment.

.

Southern Nevada - City and County Adaptive Parks and Recreation Services

Henderson Parks and Recreation. The Henderson Parks and Recreation Leisure Services provides programming for 10 participants with ASD a month through their specialized programs for individuals who are 14 and older. The majority of services for individuals with ASD are for children under the age of 14. Currently, they have 50 children with ASD who participate in general recreation programs. Their core programs are R.E.C. and B.L.A.S.T. programs. These year-round programs run Monday to Friday for approximately four hours each afternoon. The programs are designed for individuals with disabilities who are 14 years and older, any ability level. (Approximately 90 participants registered for these programs). They also offer week day and weekend programs, which meet once a week, as well as one day special events geared primarily for teens and adults. Programs change each brochure season.

The majority of services for individuals with ASD are for children under the age of 14.

Sheri Cordray, Director of Adaptive Services, noted several barriers to providing additional community-based programs. First, it is difficult to find an ample pool of qualified applicants to choose from (experience with disabilities, recreation, leadership, etc.). Second, the working budget and current budget cuts make it difficult to fund additional staff (part time and full time), supplies, facility space, vehicles, etc. for specialized programs. Third, the previous barriers make it difficult to keep up with the demand for services. Fourth, it is difficult to identify what types of recreation opportunities individuals with disabilities would like to do. They would prefer to provide services based on what people want rather than what they think people want. Finally, they struggle with getting others to "buy in" to the need for more programming. For example, they must compete for dollars and space with other who do not view the need for these services as important.

The City of Las Vegas Adaptive Programs. The City of Las Vegas Adaptive Programs provides inclusive and segregated leisure and recreation programming for an average of 30-40 youth and adults with ASD each month. There have been requests for more segregated programming for children with ASD from a local non-profit Autism agency. However, the city noted that they have difficulty in finding space and adequate staff to run specialized activities (e.g., gymnastics) for children with ASD, similar to experiences faced by the City of Henderson. The city does not keep data on primary diagnosis or secondary diagnosis nor do they count repeat participants. They are more concerned with needs, desires, and abilities of participants.

Community Based Programs for Adults with ASD

Goodfriends: Las Vegas Young Adult HF Autism/LD Meetup Group. The purpose of this program is to provide friendship, support, and fun to high-functioning young adults, ages 18-32, who have ASD, ADD, or other learning disabilities. The program primarily serves individuals in the Las Vegas/ Henderson area. The activities include a get-together once a month where individuals talk, share, and plan a fun activity. Participants then meet up to have fun at a pre-planned location. The majority of regular meetings and meet-ups will be held on Saturdays. Potential members must be high functioning and either working in the community or attending post-secondary education programs.

Links to community agencies, services and support groups are not found in any centralized location. There is inconsistency in how professionals and families receive information and supports.

Barriers and Recommendations for Community Inclusion for Individuals with ASD

Community Inclusion Barriers

- ASD is not well understood by the general public. There are misconceptions resulting from media coverage and other sources.
- Links to community agencies, services and support groups are not found in any centralized location. There is inconsistency in how professionals and families receive information and supports.
- Recreation programs for adults are more commonly segregated and there are limited supports to facilitate the use of existing community programs.
- There are limited services and supports for individuals with ASD thus hindering their participation in inclusive community environments.
- There are limited resources (e.g., financial, support) to support and guide individuals with ASD living in the community independently or semi-independently, especially for individuals who do not qualify for regional center services.
- Adults with ASD have limited access to independent and supported living housing options, therefore they are frequently found living with their family or in a group home. There are no individualized living situations (e.g., apartments) offering on-site / on-call support staff available for people with ASD. If living independently, there are limited supports to ensure success.

- While some individuals with ASD live independently without support services, some individuals with ASD need supplemental supports for decision making in independent living situations (e.g., where to live, hoe to spend money). Currently, there are limited person-centered supports to assist these individuals. It should be noted that

Adults with ASD have limited access to independent and supported living housing options, therefore they are frequently found living with their family or in a group home. There are no individualized living situations (e.g., apartments) offering on-site / on-call support staff available for people with ASD.

- Adults with ASD and their families have difficulty navigating the available services and support on a regular basis and during crises.

- Mental health services are unprepared to deal with the unique needs of individuals with ASD.

Recommendations:

1. **Initiate a state campaign to increase awareness of ASD and to educate the general public by using a strength-based portrayal of individuals with ASD. Use public service announcements to share "best practice" information about ASD and direct inquiries about ASD to reliable sources.**

2. **Develop and utilize a centralized, web-based information site which establishes all Nevada ASD supports and services in a central clearinghouse. The site should include an interactive on-line support section where parents and individuals with ASD can ask questions and receive timely answers. The site must provide information about available life-planning services to allow caregivers opportunities to prepare for when they can no longer care for children. To increase accessibility, hard copies of important information should be provided at libraries and public agencies.**

3. **Provide a single point of entry for families and individuals with ASD to access Nevada resources and support a single agency to help parents navigate the service system. Provide seamless transition from one service agency to another so parents do not have to repeat their stories and reduce/eliminate duplicate paperwork.**

4. **Develop services and supports for adults with ASD so that they may live, work and recreate within their community.**

5. **Use person-centered planning to assist individuals with ASD in personal**

decision making. Develop guidelines for persons working individuals with ASD in how to implement person-centered planning. The goal is so adults with ASD can be free to choose their living situations, receive financial information/supports, legal representation, appropriate medical and dental services, mental health services, access to inclusive recreation, vocational training, employment in their communities, etc.

Develop a support network for adults with ASD so that they may experience a desired quality of life and live free from isolation and harm.

6. Develop a support network for adults with ASD so that they may experience a desired quality of life and live free from isolation and harm.

7. Provide training and supports for individuals with ASD interested in using public transportation. Prepare public transportation employees to address the unique needs of individuals ASD and help avert crises in the community.

8. Support inclusion of students with ASD in school-based programming to encourage the development of natural supports, friendships, and appropriate social skills leading to full participation in their community as they transition into adulthood.

Provide training and supports for individuals with ASD interested in using public transportation. Prepare public transportation employees to address the unique needs of individuals ASD and help avert crises in the community.

9. Create a NEVADA AUTISM HELP & SUPPORT LINE so families and individuals with ASD can receive appropriate and timely support.

10. Develop a mechanism where adults with ASD can self-direct funding for the purchasing of services.

References

Modell, S., & Imwold, C. (1998). Parental attitudes toward inclusive recreation and leisure: a qualitative analysis. *Parks & Recreation*. Retrieved April 15, 2005, from http://www.findarticles.com/p/articles/mi_m1145/is_n5_v33/ai_20640542

Paiewonsky, M., & Tufts, S. (January 1999). Recreation in the community. *The Institute Brief,* 9(1). Retrieved June 26, 2008, from http://www.communityinclusion.org/article.php?article_id=12&staff_id=32

Walker, P, & Shoultz, B. (n.d.). Community integration report: supporting children and youth with disabilities in integrated recreation and leisure activities. Retrieved April 15, 2005, from http://thechp.syr.edu/intrec.htm

Wilhite, B., Devine, M., & Goldenberg, L. (1999). Perceptions of youth with and without disabilities: implications for inclusive leisure programs and services. *Therapeutic Recreation Journal*. Retrieved April 15, 2005, fromhttp://www.findarticles.com/p/articles/mi_qa3903/is_199901/ai_n8844788

Therapeutic Recreation Journal. Retrieved April 15, 2005, from http:www.findarticles.com/p/articles/mi_qa3903/is_199901/ai_n8844788

Public Commentary

The document concludes with public commentary from parents with children that on the spectrum. The topics in public commentary are related to Post Secondary Education (PSE), Community, and Employment. These comments and concerns shared by parents upon request from the Transition, Employment, and Community Inclusion Subcommittee.

QUESTIONS	PARENT 1	PARENT 2	PARENT 3	PARENT 4	PARENT 5	PARENT 6
Secondary Education:						
Has your child been attending the community college or UNLV?	Son attended CCSN	My son, ___ who will be 20 in May 2008, has been attending CSN (Charleston campus) part time. He is interested in the law. His idol is Judge Judy. He usually takes 2 classes per semester. He wants to take a course over the summer. I think he may ultimately transfer to UNLV.	Graduated UNLV	-	-	-
Has your child received the supports that they need at college?	No. I was so disappointed.	For the most part, my son has been receiving supports at CSN. Joe Garcia from the Disability Resource Center (DRC) has been great with ____, helping him deal with his instructors, and they with him. ____ gets extra time on tests, and has a note taker.	He was registered with the student assistance office, but needed no extra support.	-	-	-
Did your child have to drop out of college because of lack of support?	Yes. He was so frustrated due to the counseling not understanding Asperger's Syndrome.	He's still attending CSN.	No	-	-	-

QUESTIONS	PARENT 1	PARENT 2	PARENT 3	PARENT 4	PARENT 5	PARENT 6
Did your child successfully complete course work?	He actually had to drop several classes in a semester due to focusing status and inability to multitask.	He has successfully completed his coursework, especially the English classes, which are extremely difficult for him. I have helped him when he has asked for help. At present, he is taking a public speaking class, which is particularly difficult for him. CSN has tutoring for students (all students), but in the subjects where _____ needs it most, it doesn't work (i.e., English – it's not a black and white subject and each instructor has their own spin on the topic).	Yes	-	-	-
What do you attribute to your child's success or lack of success at college?	Lack of scholarship criteria (he missed by five points getting the Millennium Scholarship due to having Asperger's Syndrome, as well as voc rehab procrastinating and not understanding Asperger's Syndrome as well.	His support at CSN, our support, and the fact that he is going part time.	He was focused on a major that interested him. He had financial support to attend.	-	-	-
Community:						
Are there any concerns you have as a parent about your child transitioning into the community?	Each individual need a vocational assessment, career assessment and continuous counseling on going one has truly found a job or college degree desired.	I have many concerns about ____ transitioning into the community such as supporting himself, taking care of himself.	We had a large concern he would be able to find employment with his disability.	-	-	-

QUESTIONS	PARENT 1	PARENT 2	PARENT 3	PARENT 4	PARENT 5	PARENT 6
Do you have any programs or services that you can suggest that might help your child?	Thus far.....very limited	? I think that for someone like ____, who is extremely intelligent, but needs some support, if there were programs to make him independent, it would be a lot cheaper than if were on the dole.	No, he was successful in college and securing employment in his field of study	-	-	-
If your child has not been able to get services, what services would you like for them?	SSI Vocational Rehab transition job and school coaching	Desert Regional Center has accepted ____, but has no funding to help with In Home Services. ____ needs help in learning to shave; how to cook and clean, and finances.	N/A	-	-	-
What services has your child had?	Very little	_____ has had services from Voc Rehab. He has had an assessment through Goodwill; did a community assessment with an attorney; has used a job developer; and a job coach. Funding is a real issue. It almost seems like a lot of the agencies are redundant.	Have you experienced any problems with any services? We use national services, like the Washington Center in Washing DC to obtain a summer internship for him. There was nothing locally.	-	-	-
Does your child have a social outlet?	Very little due to lack of social skills	There's a new group, called GoodFriends, which has young adults just like ____. The group is for young adults 18-32. They usually meet once a month or every other month to plan activities, and then meet another time to do an activity. So far, they have gone bowling, movies, Springs Preserve, GameWorks, pot luck dinner, and will be doing a community service activity at a nursing home.	No	-	-	-
Is your child involved in integrated recreational activities?	(unanswered)	My son is not involved in any recreational activities.	No	-	-	-
Employment:						
Are there any concerns you have as a parent about your child transitioning into the work world?	Job coaching... individual needs maturity time as well as ongoing counseling	I have many concerns about ____ transitioning into the work world, such as an employer who understands him, as well as him adapting to the "real world ".	Yes, he interviewed numerous times, but he couldn't compete with his peers. Even when he disclosed his condition it didn't help.	-	-	-

QUESTIONS	PARENT 1	PARENT 2	PARENT 3	PARENT 4	PARENT 5	PARENT 6
What experiences has worked well for your child?	Advocacy skills	Structure has worked well for ____, as well as someone who understands ____'s idiosyncrasies.	Washington Center in Washing DC has a program for disabled students to obtain internships with federal agencies.	-	-	-
Is you child working? Has you child been looking for work but has not found anything?	He has been laid off several times to due lack of social skills. His last job was ok, but I wish he had someone advocating what is autism, etc. His job layoff has set him back.	____ is working as a front-end clerk (bagger) at Smith's. He is looking for another job that is more structured, especially the hours.	Yes he is working.	He worked at Albertson's for 1 1/2 years and did a great job. His qualifications are great.	-	-
Is your child receiving enough adequate support at work?	While working, he was just getting by on the last job and became disinterest due to lack of social peer level.	We are working on it.	So far yes.	-	-	-
Is your child able to work in their field of interest?	No. He decided to quit and try a college out of state.	____ has not been able to find a part time job at a law firm. He had a job at a law firm, but was fired because ____ decided to do things his way, instead of the way the employer wanted.	Yes, he is fully employed in his field of study with a salary that will allow him to live independently.	-	-	-

Additional Employment Questions

What has your experience been with Vocational Rehabilitation?

Parent #1

Thus far, Vocational Rehab has been a very, very negative impression. The Vocational Rehab counselor has a waiting list and it was hard to make appointments. The individual (child) loses interest due to a waiting list of three months. Then we had to go through a video tape presentation - no person to person contact of support. When we finally had our meeting with a Voc. Rehab person, the counselor was too forward, not truly understanding the level of Autism, and there was multi overwhelmingly paperwork! They do not advocate for more assessments, careers assessments, college support networking, flex to go part time instead of full time, and most of all: financial aid is not explained and scholarships are hindered for those with Autism. I was not impressed with the Voc Rehab offices.

Parent #2

Voc Rehab has been most generous with their services, although it can be a fight at times

Parent #3

My one call to them was negative. They had no programs to support high end Aspergers.

Parent #4

My son is now 20 years old and has High Functioning Autism. He has been cooperating with Voc. Rehab for 2 years. He has attended scheduled meetings and filled out all paper work, got his health card, and driver's license. In two years he has not even gotten a job interview through Voc. Rehab. VR has been difficult to work with and when we call them we're told people are out sick and it takes time and we need to be patient. Last fall, our assigned case worker wanted to remove our case because he claimed there was no response, or that we were difficult to get a hold of, which is something we've never been accused of. After a strained discussion with our caseworker, he decided to keep our case, although my son has still never received job interviews or direction. After a few more months of nothing, I have recently requested to be dropped off the VR caseload. I really don't understand why it is so difficult for my son to get an interview.

An idea I have to improve these services is to get qualified, honest, ambitious

people, trained in autism and other areas of special needs to work with employers and others. It seems there should also be more accountability with VR or other agency staff. Our VR caseworker contacted us rarely, but claimed to have left messages on my cell phone and home phone. I have talked with companies that were willing to work with my son in the program and still waiting for VR to contact them for further information. Each time we call VR we are told it takes time.... I am not sure what the placement agencies names were that contracted with VR, but we were transferred from one to another and still got the same inconsistencies. To me "The proof is in the pudding" saying is applicable in this case. Appropriate training and accountability is critical to truly assist my son and others to gain meaningful employment.

Parent #5

X hasn't actually had a lot of experience with Voc Rehab. He had a counselor, BN out in NLV during and post high school. Because of them, he was able to connect with two summer jobs through Nevada Business Services. He eventually lost the Voc Rehab--I remember her saying they had no more funding for X--because we got him a job for a year at the Deseret Industries, which is a donation-based organization of our church.

Parent #6

Experiences:

- Lack of knowledge in disability.
- No regular communication with client.
- Didn't feel supported.
- IPE was not complete till approx. 6 to 8 months after initial intake.
- Was told would work on Resume and Mock interviews which never took place.
- Didn't seem to know what options were available.

Barriers:

- Has a job offer which would involve 2 bus transfers.
- When placed at UNLV for a CBA VR should have been working on permanent job placement.
- After CBA was complete, there was no other job offer available.
- Parent found a position at CCSD and followed through with no assistance from VR.
- Again no regular communication as to what the status was for job opportunities.

Recommendations:

•I feel that VR needs to coordinate/ collaborate out in the community and develop good working relationships for their clients.

•I would like to see more training in the area of Autism for the VR case workers and more importantly the Job Developers needs to understand Autism.

•I believe that VR needs to learn how to "market" their cliental, they don't seem to understand how to present what a valuable employee this could potentially be with some support and training.

•More training and teamwork

Is your child in sheltered workshops, competitive employment, or receiving ongoing job coaching?

Parent #1

Neither. I wish college would be more proactive.

Parent #2

____ has been receiving services of a job coach, but did not get along with her; we are in the process of changing job coaches.

Parent #3 – No.

Parent #5

He's had two summer jobs through Nevada Business Services. The first, before his Junior year, was as a custodian assistant at Beatty Elementary. I believe he made $5 per hr. The next summer, Nevada Business Services arranged for X to assist in the copy room at the school. He worked with a very nice man there, and that went well. After that, I believe they assisted in getting him a job at Target--which went very badly--He was meeting the public and directing people to things--He was semi-fired. He had a job for a year at the Deseret Industries, which is a donation-based organization of our church. It went very very well. That was only for one year--and he then became affiliated with Goodwill Industries. He worked first at a place on Maryland Pwy. and that didn't go very well. So he moved out to their West Sahara location for about a year--and that went okay. After that, we assisted him in getting a job cleaning planes--that was barely okay but brief--X became fixated on a girl. It was about then that DRC arranged for X to become affiliated with Progressive Choices, a sub of DRC, who did job coaching and got X started at UNLV washing dishes. He did that for about a year and a half through them--and then UNLV offered him a full-time position washing pots and pans--he did that for about 2 years with Progressive Choices doing just follow along for minimum hours. I really

liked the employee, R, who was a Progressive Choices employee and job coach. However, I was very displeased with Progressive Choices when UNLV had to cut his hours back and we began looking for something else. The guy, J, with Progressive was actually rather ugly.

We assisted X in getting an application with the school district for custodian, and then he went on probably twenty interviews unsuccessfully until one nice head custodian decided to give him a chance. Sounds like a fairy tale, huh? During this last eight months, DRC has continued to provide funding for job coaching for X through Transition Services--his job coach is K, and she has been wonderful. I'm very pleased with them. Without her help, I don't know if X could have made probation. Because X made too much as custodian, he lost his Medicaid--However, DRC has kept him on for minimum in-home SLA and job coaching.

Complete List of Subcommittee Recommendations for Quick Reference

Combined List of Recommendations by Subcommittee

Insurance- Recommendations From Executive Summary

1. The Nevada Legislature is asked to ensure that Autism Spectrum Disorder is treated as any other medical condition, by passing insurance legislation that will:
    a. In general, require health insurance policies and the medical assistance program to cover the screening, diagnosis and treatment of Autism Spectrum Disorders in individuals less than 21 years of age. Applies to policies offered, issued, or renewed on or after July 1, 2009, to groups of 51 or more employees. Include all insurance programs in Nevada, including self-funded and self-insured plans.
    b. Benefit limits – Coverage for evidence-based behavioral therapies are subject to a maximum yearly benefit of $36,000 but no lifetime benefit caps or visit limits. After December 30, 2011, the maximum yearly benefit will be adjusted for inflation.
    Coverage is subject to co-payment, deductible, coinsurance provisions, and general policy or program limitations and exclusions to the same extent as other medical services.
    c. Authorized treatment – The treatment of Autism Spectrum Disorders includes the following medically necessary care identified in a treatment plan:
        i. Prescribed medications and any test needed to determine their effectiveness;
        ii. Psychiatric care;
        iii. Psychological care;
        iv. Habilitative and rehabilitative care, including Applied Behavior Analysis (ABA);
        and
        v. Speech therapy, occupational therapy, and physical therapy.
        vi. Allow for a Physician or Psychologist or qualified Masters-level professional to develop the treatment plan for autism spectrum disorder. An insurer may review the treatment plan once every six months, unless the insurer and physician or psychologist agree that more or less frequent review is necessary.
        vii. As a cost savings measure, allow reimbursement of Masters-level, licensed therapeutic care professionals, as well as paraprofessional therapists when working under the supervision of a Masters-level (or greater), licensed professional.
        viii. Providers – The Nevada Psychology Board, in consultation with other appropriate state agencies, will set standards for behavior specialists, a newly recognized group of service providers.

Best Practices Recommendations:

1. The Nevada Department of Health and Human Services and the Department of Education should collect data and report annually to the Governor and Legislative

Counsel Bureau the numbers of Nevada children and adults who meet the criteria for ASD.

2. Fund a Nevada Autism Registry. An Autism Registry would collect a variety of data to answer questions, support future grant proposals and provide the state with accurate numbers of those affected by ASD.

3. Fund grants to improve current data collection systems to more accurately determine the number of Nevadans who meet the diagnostic criteria for ASD, independent of or in addition to other impairments.

4. The Governor continue the Autism Task Force for an additional two years. Coordination and consistency are critical aspects of implementation planning. It is essential that Nevada develop a cohesive, integrated system for addressing the recommendations delineated in this document. Such foresight will ensure excellence and efficiency in program development, and systematically reach every child, parent and provider.

5. The purpose of the Task Force will necessarily need to be modified to reflect a change of focus toward implementation planning. In light of this, additional appointments, subcommittees or consultants could be necessary such as an individual who can speak to transition, residency and employment, since the Task Force is addressing the lifespan.

6. The Autism Task Force should develop a Best Practices & Guiding Principles document, maintaining the intent of this document in regards to defining evidence-based treatments. Legislation needs to endorse and require said document to be utilized and followed by all state agencies, providers and schools districts with dissemination to parents.

7. The Legislation needs to require state agencies and school districts across the state to recognize and support evidence-based treatments.

8. The Legislation needs to require state agencies and school districts across the state to establish training and professional development to implement evidence-based treatments.

9. The Legislation must enact legislation to require health insurance coverage for evidence-based treatments and services for ASD across the life span at recommended intensity levels without ceiling caps. And Autism treatment yearly maximum not effecting medical provision. Mirroring Arizona legislation, with the exception on caps, if with caps $50,000 per year through age 9, and $25,000 per year through adulthood. Or Pennsylvania legislation, with a $36,000 per year cap, no age requirements. South Carolina is subject to a $50,000 maximum benefit per year up to age 16.

10. The Legislation must provide additional funding to the current state autism programs (O.D.S. and MHDS) at the intensity level supported by research, increasing funding

levels to support provider recommendations based on the individual's needs or at a minimum 25 hours per week.

11. The Nevada State Health Division should support an aggressive plan to encourage screening of every child for ASD as part of routine pediatric care.

12. The Nevada State Health Division should support developmental, behavioral and Autism specific screenings for all Nevada children birth to age five years in collaboration with Nevada physicians and Early Intervention and Early Childhood Child Find programs. Results of these screenings should be tracked to determine the scope of ASD in Nevada.

13. The State of Nevada should seek additional federal funding and provide additional state funding to support increased early identification and intervention services for child at appropriate levels of intensity.

14. Provide funding to the Nevada Department of Education for state-wide traininggrants on evidence-based practices for children, youth and adults with ASD inpublic school and in the community. These funds would be used to enhance existingprograms in Reno and Las Vegas and to develop new programs in rural Nevada.

15. Provide funding to the Nevada State System of Higher Education to enhance the education and practical training of undergraduate and graduate students in behavior analysis at UNR and UNLV. Education and training for post-baccalaureate students should prepare them to sit for and pass the behavior analysis board certification examination at the associate level, and education and training for post-masters students should prepare them to sit for and pass the examination at the full, board certified level.

16. Provide state-wide funding for training to first responders, law enforcement personnel and hospital staff who contact children, youth and adults with ASD.

Education Recommendations:

17. Offer school districts incentives to develop tiered professional development for licensed staff and support staff to get additional training specific in autism

18. State support two day lecture on autism-background on autism and Discrete Trial Teaching techniques

19. State support Hands-on training for Discrete Trial Teaching

20. State support autism training teams (6 teams for Clark County School District, 2 teams for Washoe School District, 1 team for Carson City School District, and a state team to support rural districts).

21. State Department of Education support online training for teachers and paraprofessionals working with students who have autism.

22. State Department of Education support colleges to offer online or distance education college courses that meet the endorsement requirements for teachers

23. State Department of Education support training positive behavior supports in the rural districts .

24. Lower case loads for Speech/Language Therapists who support students with autism to 30.

25. Provide funding to streamline data collection that is user-friendly.

26. Legislation that supports school districts being able to develop a mentoring system to support staff serving individuals with autism.

27. Legislation to fund teachers earning their special education license and endorsement in autism.

28. Advise the Professional Standards Board to allow Alternative Route to Licensure five (5) years to complete the generalist license and autism endorsement.

29. State Department of Education assist with identifying a case load cap of 30 for Occupational Therapists working in school districts.

30. Pilot lower case load and class size so teachers can meet the paperwork demands-students with autism are in every program (general education, resource classes, and self-contained classrooms)

• Type of Program	Class Size/Case Load	w/Assistant
o Resource	10/12	12
o SELF-CONTAINED		
o Autism	4/6	6
o ECSE/Specialized	8/10	10
o Learning Disabilities	10/12	12
o Moderately MR	8/10	10
o Severe MR	4/6	6

31. Pilot changes to NAC and state IEP that identifies level of need rather than location. NOTE: similar to reporting to the federal government about percentage of time in general education rather than naming a location.
    type of service needed, consult or direct
        - push in to general education classroom
        - pull out to a intensive intervention setting, no more than 6 students with disabilities or with an assistant from 7-10 students with disabilities
    - where support will be provided (push-in to general education classroom, pull-out classroom in another room, pull-out classroom at another comprehensive campus, pull-out classroom at a special school)
        - Class Sizes
            - General education classroom, same as NAC

- Pull-out classroom at no more than 10 students with a special education teacher and an assistant

32. Require the Nevada Department of Education, in collaboration with School Districts and the Autism Task Force to develop competencies to guide paraprofessional development based on evidence-based practices and the most current research. Competencies would include knowledge and demonstration in practice. Meeting competencies would begin after entry-level. Revise the NAC's definition of "appropriately trained" paraprofessionals to include the finalized competencies.

33. Provide funding to the Nevada Department of Education for statewide training grants for paraprofessionals on evidence-based practices for individuals with ASD in public school.

34. Provide funding to the Nevada University and Community College systems to create a certification program for paraprofessionals.

35. Legislation to provide funding to school districts for paraprofessionals as a separate funded position.

36. Develop and set paraprofessional salary levels, based on a tier system of meeting defined competencies.

37. Fund Autism Coalition of Nevada, ACON, to enhance and maintain their web-site, which identifies services, providers, and support groups throughout Nevada.

38. Provide regional autism centers, which parents can go into to get general autism information, assistance, best practices, research information about treatments, and referrals to programs. Fund grant process to work within existing university and community college systems to develop regional autism centers to provide ongoing community based assistance to families in Southern Nevada, Northwest Nevada and rural Nevada.

39. Fund child specific parent education through the Connection Center in Southern Nevada and a similar center in Northwest Nevada.. The rural areas would better be served by funding a State Autism Team to provide similar services as the Connection Centers in urban areas.

Financing Comprehensive Systems of Care Recommendations:

40. The Nevada Legislature is encouraged to pass legislation requiring insurance coverage for Autism services. This legislation should:

    a. Include all insurance programs in Nevada, including self-funded and self-insured plans.

b. Disallow pre-existing condition exclusions.

c. Specify that coverage may not be subject to dollar limits, deductibles, co-payments, or coinsurance provisions that are less favorable to an insured with Autism than those that apply to a physical illness.

d. Specify that benefits must be at least as comprehensive as those provided for other neurological disorders under the policy, if applicable.

e. Require coverage for coordination time among members of the treatment team.

f. Empower the treating physician to direct the plan of care.

g. Ensure that insurance coverage cannot be denied based upon services being available through a public program.

h. As a cost savings measure, allow reimbursement of Masters-level, licensed therapeutic care professionals, as well as paraprofessional therapists when working under the supervision of a Masters-level (or greater), licensed professional.

i. Allow plan of care reviews no more often than every six months, and require that reviewers have demonstrated expertise in Autism treatment.

j. If benefits are capped, the cap must be appropriate and reasonable and the cost of heath services not related to Autism should not count against that cap.

k. Coverage must include Applied Behavioral Analysis.

41. The Nevada Legislature is encouraged to pass an Any Willing Provider law, which:

a. Is not specific to pharmacists and which includes all service providers who serve individuals with Autism.

b. Is broad in scope, applying to all or most licensed providers in the state.

c. Details a list of specialties covered by the statute or asserts that the provisions apply to all specialties licensed in the state without specifically listing any.

d. Includes a provision that reimbursement rates to such providers be consistent with similar providers already contracted with that insurance company.

e. Specifies that provider enrollment is always open and not constrained to time limits or to certain times of the year.

42. Given the investment of State resources necessary to develop an Autism Waiver, the limited number of Nevadans who could likely be served by such a Waiver, and the anticipated difficulty in getting a new Waiver approved by the Centers for Medicare and Medicaid services, it is recommended that Nevada instead increase

its investment in the existing Autism service programs through the MHDS Regional Centers and the Office of Disability Services. This recommendation may change as the factors listed here evolve.

43. The absence of a Waiver should also be offset by an increased appropriation to Vocational Rehabilitation (which offers a 4 to 1 federal match) to build transitional supports for young adults with Autism moving from high school into adult training, education and work.

44. Consider adding ABA under Medicaid State Plan services and Nevada Check Up.

Screening and Diagnostic Recommendations:

Screening:

45. The Department of Health and Human Services will conduct an ongoing public awareness campaign to increase the awareness of the early signs of ASD, and increase access to developmental, behavioral and ASD- specific screening using multimedia methods.

46. All children in Nevada will be screened with standardized developmental screening tools at specific intervals (i.e., at the 9-, 18-, and 24- or 30-month well child office visits) [12] as well as ASD-specific screening tools at age 18 months and 24 months regardless of whether a concern has been raised or a risk has been identified.

47. Create web-based ASD information and education support services that feature a variety of ASD learning opportunities, audio-visual and print resources and interactive discussion forums to provide educational opportunities for parents of individuals with ASD and professionals working with individuals with ASD.

48. Disseminate information advertising the statewide toll-free number for the Nevada State Health Division's Autism Training and Technical Support Center where families can access free developmental, behavioral and autism-specific screening for their child.

49. Develop a statewide Neurodevelopmental Disorders Registry and designate Autism Spectrum Disorders as a reportable condition in Nevada for the purpose of determining the incidence and prevalence of this condition across our State.

50. Improve statewide professional capacity for early identification of ASDs via: Training workshops on the use of standardized developmental, behavioral and ASD-specific screening tools for early care and education providers who have ongoing contact with children (e.g., community childcare providers, Early Intervention and Early Childhood Special Educators, Early Head Start and Head Start teachers).

51. Embed best practice methods for early ASD identification and referral into pre-professional preparation courses in psychology, general and special education, and health and allied health courses (e.g., nursing, speech-language pathology, occupational and physical therapy).

52. Improve coordination between state agencies responsible for developmental screening to increase efficiency and avoid duplication of efforts.

53. Provide health care professionals (e.g., pediatricians and other physicians, nurses) access to training in the recognition of "red flags" associated with ASD, the administration of screening tools and utilization of appropriate referral sources. The goal of this recommendation is to lower the age at which children are identified with ASD and other developmental disorders in Nevada with an ultimate goal of identifying children between 18 and 24 months of age.

54. Increase the number of children and youth in Nevada who have access to a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent.

Diagnosis and Eligibility:

55. ASD diagnosis, evaluation and assessment are conducted by a team of trained professionals experienced in identifying and assessing ASD. An ASD team should include a physician and a licensed clinical or school psychologist, a licensed speech-language pathologist, and a licensed occupational or physical therapist. Diagnosis of Autism is made by observation of a child over time across several meaningful settings and involving opportunities for the child to interact with familiar and unfamiliar adults and children. A careful history of the child and family (i.e., birth, medical, developmental, social and family histories) should be recorded and considered in a differential diagnosis of Autism.

56. 12. Create a University of Nevada Center of Excellence in Autism which includes representation from a variety of health and education departments. The Center will provide ongoing training and support to professionals and programs working with children and families living with Autism.

57. Develop and disseminate statewide standards for ASD screening, diagnosis, and referral and develop and disseminate a comprehensive service delivery model to improve consistency and collaboration of services for individuals living with ASD across systems of care in Nevada.

58. Develop a train-the-trainers model, in which professionals from diverse Nevada communities receive ongoing training in best practices in the diagnosis, assessment and treatment of ASD. The Autism Training and Technical Support Center will provide ongoing support to professionals in their home communities to encourage the development of local ASD diagnostic teams. These community professionals will, in turn, provide ongoing professional in-service training and technical assistance to improve the quality of educational and treatment services to individuals and families living with ASD.

59. Parents' concerns about their child's development will be taken seriously from the beginning. An autism-specific screening instrument will be given to the child at the time the parent expresses a concern (e.g., pediatrician's visit, early intervention intake visit). Procedures to obtain an appropriate diagnosis will also be started at that time ensuring that children will receive an appropriate diagnosis within 60 days of expressing their concerns to a professional.

60. Ensure that each child who meets the criteria for one of the several Autism Spectrum Disorders will have Autism Spectrum Disorder recorded as his or her eligibility status. The generic Developmental Delay status will not be used for children meeting the criteria for ASD.

61. State agencies and Nevada institutions of higher education will collaborate to ensure that all of Nevada's independent school districts and Nevada Early Intervention Services statewide will have appropriately trained Multidisciplinary Teams (MDT) to provide competent evaluation and assessment of ASD. With the family's informed consent, School Districts and Early Intervention Services will engage proactively with families to share the results of ASD evaluation and assessment with the child's primary care physician and other community professionals. Early Intervention Programs and School Districts will demonstrate that they have informed families of the availability of those services and have actively assisted families in obtaining a medical diagnosis and referral to other public and nonpublic services. A medical diagnosis of ASD permits families to pursue other services over and above the services required by the child's Individual Family Service Plan (IFSP) or Individual Education Plan (IEP).

62. Reform medical insurance coverage to ensure that developmental and autism-specific screening is a covered service.

Training, Certification, and ABA Recommendations:

The demand in Nevada far exceeds the supply of practitiioners specializing in the field of Behavioral Sciences to address this critical shortage. A systematic plan needs to be implemented to:

63. Increase Nevada's capacity to produce a sustainable workforce of behavioral analysist credentialed by the nation's Behavior Analysis Certification Board (BACB) to serve individuals of all ages living with Autism Spectrum Disorders across their lifespan.

64. Support Nevada's system of Higher Education to provide undergraduate and graduate students access to academic training and supervised practical experiences needed to achieve this end.

65. Enhance UNR and UNLV's ability to devote their state-appropriated resources to hire faculty who specialize in the field of behavior analysis through the Psychology departments.

Transition, Employment and Community Inclusion Recommendations:

Transition:

66. Nevada will develop a comprehensive statewide system to accurately identify the number of individuals with autism. The state will establish and maintain a statewide registry of individuals with ASD. Participation should include parents, guardians, and individuals with ASD as they are the primary stakeholders in developing future appropriate statewide services and obtaining funding. Information will be kept confidential and its use be determined by the Nevada Autism Task Force.

67. Each year, all Nevada school districts will report the number of students with a primary and secondary diagnosis of ASD. The purpose is to obtain an accurate count of the number of school-age individuals with ASD.

68. The Nevada Department of Education (NDE) will collect post-school outcome data through the State Performance Plan's Indicator 14 or comparable data collection method for students with a primary or secondary diagnosis of ASD. Life Tracks, Inc., who currently collects the data for the NDE, will survey a representative sample of individuals with ASD each year. The 2008 State Performance Plan (SPP) data for Indicator 14 only includes students with learning disabilities, mental retardation, and emotional disturbance.

69. Designate an independent organization to provide leadership in coordinating autism services statewide. This organization will help develop a web-based, clearinghouse site for ASD services and include information from various theoretical orientations. This organization will also provide an independent annual review of statewide progress on Nevada Autism Task Force recommendations.

70. Futures planning for each student beginning at age 14 (although earlier is preferred). The purpose is to identify desired post-school outcomes and develop an action plan to help the students work toward those goals. Futures planning encourages person-centered planning and helps facilitate movement toward a common vision for the future.

71. Clarify roles and responsibilities of teachers and transition specialists in the transition planning. Provide both professional development opportunities for teachers and training for parents to clarify their roles in the transition process.

72. Teacher preparation institutions should collaborate to identify desired outcomes of transition courses in the state. A greater focus should be in preparing teachers in the futures planning and transition planning process.

73. Develop a university training program to prepare transition specialists across the state. Currently, few specialists are available to bridge the gap between school and community-based services. A possible funding source includes federal personal preparation grants.

74. Fund additional transition specialists to assist school personnel in connecting all students with disabilities to community agencies and post-school opportunities.

75. Increase the capacity of the current local education agency (e.g., district) transition and post-school programs to provide services to students with more significant disabilities.

76. Create a transition resource guide that is distributed through schools and community agencies to parents/ individuals with ASD beginning at age 14.

77. Restructure the State of Nevada Transition IEP document to facilitate person-centered planning. The students' post-secondary goals should guide the planning process, including selecting appropriate transition assessments, developing an action plan, and creating annual goals. To assist implementing the transition IEP, the document should identify necessary steps and the person responsible, which may include parents, students, community service providers, local education agencies, and teachers.

78. Establish a protocol for providing social skills and life skills training for students with ASD without regard to educational placement. Opportunities should be provided during school, in after-school programs, and in summer programs. Students should learn and practice skills in the most integrated settings possible. The goal is to prepare students to live, work and recreate in their community.

79. High school students with ASD, including students pursuing a standard diploma, will have work experiences in multiple settings commensurate with their abilities prior to exiting school. Work opportunities will explore interests, determine strengths and identify areas of need and support. Opportunities during school, after school and/or school vacations should be available.

80. Mandate that teachers, support staff (including principals), and transition specialists receive education and training on the needs and supports for students with ASD. Provide access to autism specialists as mentors, classroom consultants and teacher support group leaders.

81. Provide exposure to transition-age youth with ASD and their parents to Post Secondary Education (PSE) environments and options, including life enrichment programs, campus recreation, activities, events, and clubs. Exposure will include training in "entitlement" vs. "eligibility" reflected in changing from a nurturing education system to those requiring self-advocacy skills.

82. Equip Institutions of Higher Education (IHE) with the tools and resources (e.g., training, financial assistance) to assist individuals with ASD in developing routines, socializing, and adapting to college life.

83. High school guidance and vocational rehabilitation counselors will provide all students with ASD and their parents information about post-secondary education requirements, opportunities and supports by age 16. Information can be presented in collaboration with the IEP team.

84. Provide students with instruction to develop self-determination skills, including goal setting, self-awareness, choice making, self-advocacy, self-regulation, and problem solving. In a post-secondary education environment, for example, the student with ASD will decide when to inform the instructor about his/her disability,

if they choose to at all. The New England Asperger's Association suggests that "early disclosure to appropriate college personnel improves the chances for success, and minimizes the chances of misunderstandings or unfortunate incidents…We highly recommend that you give college information about yourself and about AS after you are admitted and before the first semester" (Jekel & Loo, 2003).

Employment:

85. During the intake process, have a facilitator present who knows the applicant. This person must be someone that the applicant feels comfortable with and someone the applicant wants involved in the intake process. If the applicant is nonverbal or cannot answer a question, rephrase the question or allow the facilitator to answer. Determine if the person with ASD has a legal guardian and include the guardian if possible and/or feasible.

86. Consider the social aspects of different job environments when making a job placement. Discuss with coworkers the characteristics and behaviors of people with ASD. Build in natural supports so the person can have someone to go to if there is a problem or a need for clarification. Communicate information directly and avoid metaphors and idioms, which may be interpreted literally. For example, ask, "How are you today?" rather than "What's up?" Provide consistency of instruction given by the same person if possible. Do not depend on nonverbal cues—such as telling an individual, "Your job is finished," standing up to leave, and expecting the person to follow. The person may need a verbal directive such as "It is time to leave the room and go to the second workstation; follow me, please." For the nonverbal person with ASD, use a communication aid such as a picture cue system or some form of assistive device that aids the person with communication. People with ASD often require extra time to process conversation.

87. Any time a request is made, wait for a response before repeating the statement. Don't ask a series of questions. Tell the person, using clear, concise, concrete language, what you want him to do. Model the appropriate behavior. Structure, order, routine, and clear rules and assignments are the key to success for a person with ASD (Hurlbutt & Chalmers, 2004; Doyle, 2003).

88. Secure a job that requires limited problem-solving skills. Provide a job task which, once started, can be finished without interruptions. One example is an assembly job that requires the same steps every time it is performed.

89. When teaching the job, have the person with ASD restate the directions. Break directions down into simple steps, with time limits delineated for completion of a task. Provide a consistent work station or work set-up. Ensure that the employee knows what to do when the task is finished. Provide regular reminders and positive feedback.

90. Develop a system for transitioning from one task to another. Be sure that during a break or downtime, the person with ASD has a preferred activity to engage in, such as a video game.

91. State differences of opinion calmly and in a nonconfrontational manner. Avoid suggestive and indirect language (Myles & Simpson, 2003).

92. Provide training to coworkers and supervisors in how best to solve a problem. Explain the situation in terms of the problem and not the person (Shattuck, 2001). Attempt to emphasize the concrete aspects of the task, not the big picture. Teach the job right the first time by establishing a routine as quickly as possible. For example, use a pictorial chart of the hierarchy of who to go to if there is a problem (Emmett, 2004).

93. Social skills that are needed on the job must be trained, just as technical skills are trained. Social skills are critical for successful employment. Two methods for teaching appropriate social skills are role playing and video modeling. All of the references listed in this chapter are excellent resources for teaching social skills.

94. Discuss with coworkers the individual's response to certain situations, such as lack of eye contact, failure to make small talk, or walking between two people who are talking. Others may perceive these responses as rudeness. However, they should be explained as a common characteristic of autism. Job coaches and other staff must be very consistent in the way they teach the person social behavior necessary for successful employment.

95. Respect the sensory sensitivities by designing the work area to minimize seriously distracting sights and sounds. For example, allow the individual to wear ear plugs or to listen to his or her choice of music through headphones; use tinted glasses to minimize the effect of fluorescent lighting or other harsh light; have the employee's work station near a window that provides natural light; and if the employee is required to wear a uniform, allow modifications that will make the uniform more comfortable.

96. A useful technique for self-regulation could include relaxation and deep breathing exercises. Schedule sensory breaks throughout the work day to assist the employee in coping with the busy work environment.

97. Be sure that the solution to the person's sensitivities is not degrading and does not call undue attention to the problem. Do not sneak up on someone with ASD or startle them. If the person's back is turned, announce yourself. If the person gets too close to you when talking, calmly ask the person to move back a step. A quiet setting out of heavily trafficked areas is usually the best work location for someone with ASD (Grandin & Duffy, 2004). If clutter is a problem, develop a plan (and share it with the person with ASD) to get things organized into neat specific categories. People with ASD are "systemizers," which could be a real asset on a job.

98. Carefully match the job with the individual's interests and skills. Analyze the job and make adaptations using jigs and other prostheses that can help compensate for deficits in fine and gross motor skills. Consult with an occupational therapist who could assist in making accommodations for the individual (Myles & Simpson, 2003).

99. Build on the compulsions and rituals of the person whenever possible. For example, a person who memorizes the rules of grammar will probably do well in a job requiring coding and classifying books or materials.

100. Facilitate the interview process with the applicant through role playing. Highlight the applicant's strengths. Have a resume prepared. Practice rote responses and have four or five questions prepared for the interviewer. Assist the person with ASD in planning for and dressing appropriately for the job being sought. If it is a mechanic's job, a suit and tie would not be appropriate (Grandin & Duffy, 2004); however, the person with ASD will not know what is and what is not appropriate dress. In lieu of the traditional job interview, an arrangement could be made for the employer to make available short-term job try-outs, in order to demonstrate the person's abilities and strengths (Hagner, 2005). Three or four different on-the-job try-outs could be helpful in assessing desires and capabilities. A well-trained job coach will make sure that the employer perceives the person with ASD as an asset and helps to ensure that the job will be done as the employer expects.

101. If possible, procure a job with duties that enable the person's challenging behavior to become an asset. For example, an individual who likes to break glass could work in a glass recycling job which requires the employee to toss glass items into a large bin. A person with ASD whose intense interest is putting together a 500-piece jigsaw puzzle would probably be successful in an intricate assembly job. The employer and coworkers must feel confident that if a behavior problem occurs, the job coach or supporting agency will effectively and efficiently handle the situation with a minimum of worksite disruption. The job coach must systematically identify the problem and then design and implement a solution. Personal networking and the development of ongoing relationships with employers must be maintained. If the person is presently taking medication to assist in controlling anxiety, depression, or any other comorbid condition, make sure assessments are made on a regular basis to ensure that he or she is taking the medications properly

102. When training a new set of job skills, keep the conditions consistent until the employee is responding correctly on a regular basis. Then gradually fade the instructions and prompts as the employee begins to acquire the skill (Scheuermann & Webber, 2002).

103. Provide support during transition from one task to another. Doing one task at a time is more suitable for the person with ASD (Grandin & Duffy, 2004).

104. Scheduled job duties need to follow a predictable pattern. Transitions need to be carefully planned and carried out gradually. When change/exceptions must occur, give the employee with ASD as much notice as possible and explain the change. For example, his desk must be moved. If possible, give him choices in some aspect of the move, like which way his desk faces in its new place. Facilitate generalization of skills by briefly retraining the task in the new work environment (Emmett, 2004).

Seeking Employment:

105. Using a standardized data collection tool, collect employment data – such as length of job search, time between employments, and locations of employment outcomes (e.g., center-based workshops, enclaves, competitive jobs) – from disability-based employment agencies (i.e., vocational rehabilitation, private agencies, and non-profit organizations) about the employment services sought and obtained by individuals with ASD.

106. Employment agencies and services (e.g., vocational rehabilitation, private organizations) will promote successful employment outcomes for individuals with ASD and share information with potential employers.

107. Develop a promotional campaign aimed at educating businesses on the benefits of employing people with disabilities (e.g., brochure, radio announcements, television broadcasts). The outcomes are to increase awareness among potential employers and increase the job bank.

108. Provide employment agencies and services with a networking tool designed to increase access to and relationships with employers who can provide volunteer opportunities, work experience, and/or long-term employment.

109. Provide monetary incentives to employment agencies and service providers who secure meaningful, long-term employment (90 days or more) for individuals with ASD considered "hard-to-place."

110. Provide employment agencies and service providers, prospective employers, and current employers incentives to provide employee training about ASD and developing natural supports (those not requiring paid supports) to improve opportunities for long-term employment

111. Provide a variety of opportunities for individuals with ASD to obtain work experience in the areas of abilities and interests and use those opportunities to assess job potential. Utilize job-carving strategies to find job niches matching employee and employer needs.

112. Educate all employment service agencies, including Vocational Rehabilitation and approved contractors, on the Personal Challenges #1 through #9 experienced by individuals with ASD as presented in Chapter 5 of 32nd IRI Rehabilitation of Individuals with Autism Spectrum Disorders.

113. Vocational Rehabilitation will provide services from an ASD consultant or create an in-house position responsible for ongoing ASD education to train counselors, staff and potential employers. The committee recommends that Vocational Rehabilitation refer to the recommendations found in this document and Chapter 5 of 32nd IRI Rehabilitation of Individuals with Autism Spectrum Disorders in developing training modules.

114. VR counselors seeking job coaches should look for these personal attributes:

- Great communication skills
- Intellectual curiosity
- High energy level
- A striving for excellence
- Initiative; being a self-starter
- Respect for the dignity and worth of a person with ASD
- Keen sense of appropriate dress for self and person with ASD, taking into account the culture of the job and community
- Keen sense of grooming and personal hygiene
- Creativity

115. In addition, VR counselors who find job coaches with these attributes should train them for specific skills:

- General knowledge of characteristics of autism
- Understanding of the "theory of mind" (see Glossary)
- Knowledge of positive behavior supports and how to implement them
- Skill to assess the sensory needs of the person with ASD and to modify the work environment to meet these needs
- Skill to conduct a functional assessment of behavior
- Ability to communicate with the person with ASD
- Ability to support the person with ASD to ensure success on the job
- Ability to use information from a functional assessment of behavior to minimize challenging behavior
- Ability to manage challenging behavior with positive behavior supports
- Ability to coordinate information from a task analysis of the job and needs of the person with ASD to provide the best level of support
- Ability to address employee/employer relations

116. Job coaches and their supervisors must be knowledgeable regarding the range and type of behavior and challenges faced by the person with ASD in the workplace and must be capable of designing supports that enable success on the job (Department of Public Welfare, Commonwealth of Pennsylvania, 2004). Job coaches must be trained and have first-hand knowledge of the job. It is important to teach the job skill in the setting where the person with ASD will be working. This should minimize the need to generalize from cues in the training setting to cues in the work setting (Smith, 1990).

117. A job coach who knows and understands the person with ASD is essential to successful job placement (Autism Society of Delaware, 2005). Experienced and qualified job coach trainers should mentor less experienced job coaches. A career path in job coaching should be encouraged and compensated at a higher level. Perhaps the Association of Community Rehabilitation Education could develop a certification for job coaches. Collaboration with programs such as the Commission on Rehabilitation Counselor Certification to mandate ASD training for certified rehabilitation counselor continuing education hours is recommended. Staff support ratios must be individualized and may vary from time to time, depending on life and job circumstances. Job coach support should be faded gradually and systematically. In some cases, continual job coach support may be necessary for long periods if the person with ASD is to maintain employment.

118. College and university departments who train VR professionals need to provide coursework and practicum experience in ASD. Federal, state, and regional administrators of VR should provide in-service training for all professional staff in their departments to work with persons with ASD.

119. The Rehabilitation and Continuing Education Program should increase training

in ASD… The leadership of VR agencies should conduct in-service training and utilize providers in the community who have experience and expertise working with adults with ASD. Information on existing community providers in the U.S. can be found at the website of the National Association for Residential Providers for Adults with Autism (NARPAA; www.NARPAA.org).

120. The Rehabilitation Services Administration (RSA) should collaborate with other federal agencies to secure funding for the long-term support needed when VR services end. At this time there is no mandate for such a funding arrangement. Medicaid's Home and Community Based Waiver Program will fund job coaches, but that support is not mandatory. The lack of funding for long-term support seriously jeopardizes employment for this vulnerable population. The system needs to provide a seamless continuum of services.

121. Universities should collaborate with the public and private sector in the autism community for outcome-based applied research on promising practices for successful employment, such as

- The application of technology using video modeling
- Determination of the best job match
- Social skills training for adults
- Job coach training
- Development of natural supports

122. A transition plan with the parents/guardian, the individual, the school district, the community disability agency, and the VR counselor should be developed and implemented by age 16 for the person with ASD.

123. At age 16 an application for developmental disability long- term funding should be completed and submitted so VR services can start at age 21, or upon leaving school.

124. A good choice for a vendor would be an agency that has experience delivering services for adults with autism. For contact information on experienced agencies, go to the www.NARPAA.org website. The Autism Society of America website (www.autism-society.org) is another resource. Websites on autism should include information and links regarding employment of persons with ASD. If autism-specific services are not available in your area, attempt to find a community developmental disability agency that would be willing to be trained in autism. Training should be provided by a specialist in adult autism issues and needs. Use the NARPAA Standards, which are located in Appendix F, for evaluating vendor staff qualifications. Given the shortage of knowledgeable vendors, the VR counselor may need to provide case management for the person with ASD.

125. Measure the impact on employment for persons with ASD.

126. Determine a baseline from the RSA-911 report (See Glossary) for persons with ASD.

127. Periodically review the RSA-911 report over the next 5 years to determine the impact.

128. Ensure that websites of autism organizations contain links to the IRI document.

129. Review this IRI document in 5 years and update it with current information, then redisseminate the information.

130. Develop a network of resources of VR counselors and autism providers. Provide meaningful opportunities for the groups to work together.

Community Inclusion:

131. Initiate a state campaign to increase awareness of ASD and to educate the general public by using a strength-based portrayal of individuals with ASD. Use public service announcements to share "best practice" information about ASD and direct inquiries about ASD to reliable sources.

132. Develop and utilize a centralized, web-based information site which establishes all Nevada ASD supports and services in a central clearinghouse. The site should include an interactive on-line support section where parents and individuals with ASD can ask questions and receive timely answers. The site must provide information about available life-planning services to allow caregivers opportunities to prepare for when they can no longer care for children. To increase accessibility, hard copies of important information should be provided at libraries and public agencies.

133. Provide a single point of entry for families and individuals with ASD to access Nevada resources and support a single agency to help parents navigate the service system. Provide seamless transition from one service agency to another so parents do not have to repeat their stories and reduce/eliminate duplicate paperwork.

134. Develop services and supports for adults with ASD so that they may live, work and recreate within their community.

135. Use person-centered planning to assist individuals with ASD in personal decision making. Develop guidelines for persons working individuals with ASD in how to implement person-centered planning. The goal is so adults with ASD can be free to choose their living situations, receive financial information/supports, legal representation, appropriate medical and dental services, mental health services, access to inclusive recreation, vocational training, employment in their communities, etc.

136. Develop a support network for adults with ASD so that they may experience a desired quality of life and live free from isolation and harm.

137. Provide training and supports for individuals with ASD interested in using public transportation. Prepare public transportation employees to address the unique needs of individuals ASD and help avert crises in the community.

138. Support inclusion of students with ASD in school-based programming to

encourage the development of natural supports, friendships, and appropriate social skills leading to full participation in their community as they transition into adulthood.

139. Create a NEVADA AUTISM HELP & SUPPORT LINE so families and individuals with ASD can receive appropriate and timely support.

140. Develop a mechanism where adults with ASD can self-direct funding for the purchasing of services.

Workforce Recommendations:

141. Increase Funding for ASD Programs in Critical Shortage Areas. Direct service provider professions with critical shortages include special education, speech/ language therapy, applied behavior analysis, and adult vocational services. The Nevada Legislature must create line item budgetary funding for critical shortage area programs at UNLV, UNR, and Nevada's other colleges. Funding would support the hiring of faculty to train direct services providers, tuition for students, and infrastructure to support programs.

142. Maintain Funding for Nevada's System of Higher Education at Parity with the National Average. Budget cuts to the Nevada System of Higher Education compromise existing and future programs to train direct services providers. As one of the fastest growing states in the nation, it is critical for Nevada's System of Higher Education to keep pace with increasing demand for ASD support professionals. Maintaining a reasonable level of funding for Nevada's System of Higher Education will help to ensure that programs continue and grow.

143. Create Incentives for ASD Professionals to Stay in Nevada. To stem the flow of ASD professionals out of state, provide incentives, such as signing bonuses and tuition reimbursements, for professionals to remain in their current positions. Support Alternative Route to Licensure (ARL) Programs for teachers to attain autism endorsements. Initiate professional certification for paraprofessionals working with students with ASD to enhance the quality of classroom instruction.

144. Initiate Professional Training Programs that Target Adult Nevadans with ASD. Services that cater to adults with ASD are almost non-existent in our state. Many adults with ASD, particularly higher functioning individuals, are capable of working and living independently with professional support. Programs that target professionals who work with older populations will increase the capacity of adults to live and work more independently.

145. Secure Federal Funding to Support Professional Training Programs. Federal assistance is available to defray the costs of ASD professional training programs. The Nevada System of Higher Education could secure federal funding to match state revenues expended on ASD programs. Potential sources of federal monies

include competitive grants and contracts from the U.S. Department of Education and the U.S. Department of Health and Human Services. Nevada System of Higher Education colleges and universities should collaborate for procurement of funds to support collaborative programs across units.

146. Develop a 10-Year Strategic Plan to Address Nevada's ASD Workforce Needs. Nevada's population will change dramatically in the next ten years. Ongoing planning is necessary to understand the changing demands for ASD professionals. The Nevada Autism Taskforce should develop a 10-Year Strategic Plan to address the state's needs for both primary and peripheral ASD service providers. The strategic plan should include ongoing and formal assessments of professional preparation needs.