

2008 REPORT



OF THE **NEVADA AUTISM TASK FORCE**

AN ACTION PLAN FOR NEVADA'S LEGISLATORS AND POLICYMAKERS

EXECUTIVE SUMMARY

RALPH TODDRE, CHAIRMAN

JULY 31, 2008



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,

A handwritten signature in black ink, appearing to read "Ralph Toddre".

*Ralph Toddre
Chairman*

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 understanding 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 its 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 and 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 its 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.

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

Incidence of Autism Spectrum Disorder

- 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.

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.

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

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.

2. The Nevada Legislature is asked to pass legislation that makes permanent the Autism intervention program currently funded in budget account 3266 in 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):
 - 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 requires screening and diagnosis of ASD.

**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
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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 profes-
sionals 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.

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.

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

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.
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 a pilot would take place in Southern Nevada, Northern Nevada and Rural Nevada.
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.