

State of Nevada Autism Task Force
Best Practice Guidelines Subcommittee
MINUTES

Tuesday, June 3rd, 2008
Teleconference

Members Present: Jan Crandy, Randy Figurski, Dr. Ron Leaf, Richard Thompson, Diane Branson, Valerie Soto, Teri Vaughn Debra Meinberg, Dr. Pat Ghezzi, and Assemblyman James Ohrenschall.

Members Absent: Cynthia McCray, Estleen Westby, Dr. Matt Tincani, Dr. Nancy Sylvania, Erik Lovaas, and Jennifer Van Tress.

Guest: Nicole Kalkowski

Staff: Melanie Stevens

WELCOME AND INTRODUCTIONS:

Jan Crandy opened the meeting at 2:05 pm by welcoming those present and asking all to introduce themselves.

APPROVAL OF MINUTES:

Assemblyman Ohrenschall motioned to approve the minutes from the May 13, 2008 meeting of the Best Practice's subcommittee. Mr. Figurski seconded and the motion carried unanimously.

RECOMMENDATIONS FOR ISSUES AND FINDINGS:

Ms. Crandy circulated a new document of Issues and Findings taken from the list of issues and findings discussed in previous meetings (see below, pgs. 3-6). Ms. Branson suggested adding a title/heading to each recommendation. The committee agreed on including Screening, Financing, Autism Prevalence in Nevada, as titles for each sections. **Dr. Ghezzi will rewrite the issues and findings for training in University Systems from the recommendations list. Mr. Figurski will confirm the data in the first recommendation and finalize it. Ms. Crandy will address a stronger dispute resolution system some where short of the complaint process to recommend to the Task Force.**

DEFINING BEST PRACTICE'S FOR ADULTS:

Ms. Crandy circulated a new document listing the Issues and Findings from the information Dr. Sylvania circulated last meeting concerning the rights and services for that should be available for adults living with Autism in Nevada. **Ms. Crandy will add the source of her information in the findings. Mr. Thompson suggested adding to the item in the conclusion concerning 'supports and services for life long care', language for support in post-secondary education. Ms. Crandy will add a bullet for**

access to insurance coverage for adults. *Mr. Thompson moved to approve the Adult portion of the Best Practices recommendation. Ms. Branson seconded and the motion passed.*

CONFIRM NEXT MEETING DATE:

The committee agreed to meet again on Tuesday, June 9, 2008 at 2:00pm to finalize their recommendations to Nevada Autism Task Force.

PUBLIC COMMENT:

Dr. Ghezzi thanked Ms. Crandy for the putting the recommendations together and spending so much time on it.

ADJOURNMENT:

With no other business to address Mr. Figurski made a motion to adjourn. Dr. Ghezzi seconded and the meeting adjourned at 3:10 pm.

Issues

In Order to state true issues we need accurate data. One of Nevada's downfalls is the lack of data that exist. 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 incorrectly labeled developmentally delayed. While other state agencies can only count the population they are serving, those on wait list and those who have applied for services.

Findings

Using the recognized statistic of 1 in 150 children, there should be at least 5,176 Nevadans ages 0-21 years old. *(Based on 776,333 age specific population, 2005)*

961 ages 0-3 yrs *(based on 144,517 age specific population, 2005)* NEIS last reported numbers by Dr. Wei Yang were only 150 children.

Nevada school districts current count is 2,559 students with the single label of ASD.

A recent grant allowed Dr. Wei Yang and associates to start pulling data from agencies across the state. However without funding this program cannot continue.

Recommendation:

The Nevada Department of Health and Human Services 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. (3)

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.

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.

Issue:

Individuals with ASD are being diagnosed late and not receiving the interventions needed; this is true for children of all ages, and is especially problematic for minority populations.

Findings

Currently the average age of diagnosis in the U.S. is between 4 and 5 years of age. 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 wait to be diagnosed.

An alarming statistic, Dr. Wei Yang stated was there are more children diagnosed with white educated parents. A fact which could indicate access is being given to those children whose parents know to advocate for a diagnosis and services.

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.

Recommendation:

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

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.

(2)

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. (4)

Issue:

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.

State Medicaid does not cover Autism specific treatments.

As more and more children are diagnosed, the fiscal impact on the state and school districts resources will be astronomical.

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.

Nevadans with ASD need insurance across their lifespan. Insurance coverage should support the needs across all ages. Insurance should provide coverage for evidence-based treatments at recommended intensity levels. It should provide for medical coverage including diagnosis and evaluations.

Recommendation:

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. (1)

Mirroring Arizona, with the exception on caps, \$50,000 per year through age 9, \$25,000 through adulthood, or Pennsylvania, with a \$36,000 per year cap no age requirements.

Some ideas for Recommendations

- 1) Implement legislation that requires health insurance coverage of evidence-based interventions and services for individuals with ASD across the lifespan.
- 2) Develop an aggressive plan to encourage screening of every child for autism as part of routine pediatric care.
- 3) Improve data collection systems to more accurately determine the number of Nevada children who meet the diagnostic criteria for Autism Spectrum Disorders, independent of or in addition to other impairments.
- 4) Justify and seek additional funding from the State Legislature for increased early Autism identification and intervention at appropriate levels of intensity.
- 5) Ensure services for children with autism are based upon scientifically validated procedures.
- 6) Ensure that services to children with Autism Spectrum Disorders include systematic instruction procedures focusing on both the acquisition of skills, and the decrease/elimination of interfering behaviors.
- 7) Require ongoing evaluation of Autism interventions using controlled studies and subject to the rigors of good science. Ongoing evaluation should minimally include a credible method of evaluation, and criteria for determining whether to terminate or continue the intervention.
- 8) Identify and recruit qualified behavior analysts from within and outside of Nevada as required to meet current service needs. Practitioners of applied behavior analysis require specialized training in addition to that normally gained by professionals specializing in behavior impairment, special education, child development or psychology. Increased demand for applied behavior analysis will precipitate the need for professional development resources to ensure ABA practitioners have sufficient and appropriate training.
- 9) Provide ASD training designed especially for first responders, including law enforcement.
- 10) Development of a statewide plan for the provision of training opportunities for:
 - a. paraprofessionals, including but not limited to: 1:1 aides, instructional assistants; teaching assistants, paid-parent-helpers, school nurses, etc.
 - b. families (including foster and extended family members)
 - c. professionals, including but not limited to: special educators, general educators, occupational therapists, physical therapists, mental health professionals, speech and language pathologists, job trainers, employment counselors, etc.

At a minimum, service providers should receive training in elements of effective service delivery. These elements include, but are not limited to:

- a. multi-domain curriculum content
- b. highly supportive teaching environments and generalization strategies
- c. need for predictability and routine
- d. functional approach to problem behaviors
- e. transition
- f. family involvement and support
- g. data collection
- h. evidence-based treatments
- i. positive behavior supports

11) The state must make an investment in the implementation of evidence-based practices (EBP) Evidenced-based practices take root from rigorous evaluation and research, are reproducible and are effective. The implementation of EBPs must encompass screening, evaluation, treatment, housing, and family support across the lifespan.

- a. Produce guidelines that are followed by all state, school and county entities.
- b. Assure quality control of delivery of services and information.

ADULTS

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.

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.

Source:

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 who will be adults soon, the commitment to

make this possible for all of them will have to be huge. **NV Department of Education, children ages 13+*

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 Autistic Spectrum Disorders deserve services which are delivered using evidence-based practices:

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;

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 care;

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

