

State of Nevada Autism Task Force
Best Practice Guidelines Subcommittee
MINUTES

Tuesday, April 22nd, 2008
Teleconference

Members Present: Jan Crandy, Randy Figurski, Dr. Matt Tincani, Dr. Pat Ghezzi, Dr. Nancy Sylvania, Erik Lovaas, Dr. Ron Leaf, Diane Branson, Debra Meinberg, Teri Vaughan, Valerie Soto, and Jennifer Van Tress.

Members Absent: Assemblyman James Ohrenschall, Cynthia McCray, Richard Thompson, and Estleen Westby.

Guests: Nicole Kalkowski, Joan Shaffer, Jan Marson, Kristin McIntyre, Joanie Ferguson, and Dr. Dean Ward.

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:

Dr. Tincani made a motion to approve the minutes from the March 7th, 2008 meeting of the Education subcommittee. The motion was seconded by Mr. Figurski and the motion passed unanimously.

RE-DESIGNATION OF SUBCOMMITTEE MEMBERS:

As chairperson of this subcommittee, Ms. Crandy re-appointed people on the list of subcommittee members to either voting members or interested parties, depending on their availability to participate in the subcommittee business. *Voting members now include: Jan Crandy, Randy Figurski, Dr. Matt Tincani, Dr. Pat Ghezzi, Dr. Nancy Sylvania, Erik Lovaas, Dr. Ron Leaf, Diane Branson, Debra Meinberg, Teri Vaughan, Valerie Soto, Jennifer Van Tress, Assemblyman James Ohrenschall, Cynthia McCray, Richard Thompson, and Estleen Westby.*

FINALIZE BEST PRACTICE:

Ms. Crandy circulated a list of bulleted items beginning with “In Nevada, individuals with Autism Spectrum Disorders...” (see below). The committee had gone through this document at their last meeting, Ms. Crandy made the suggested revisions, and the committee accepted the new document. *Dr. Sylvania motioned to accept the bullets for the children with autism as read. Mr. Figurski seconded and the motion passed. Dr. Sylvania will coordinate with Ms. Westby and Ms. Flo LaRoy to develop bullets for the adult section of the document.*

DEFINITION OF EVIDENCE-BASED PRACTICES:

Ms. Crandy circulated a definition of what is an evidenced based practice (see below). The committee agreed the document needed to be reduced. **Dr. Tincani agreed to condense the document to make it more readable and will bring it back to the next subcommittee meeting.**

DISCUSSION OF RECOMMENDATION:

Ms. Crandy circulated a list of recommendations for the committee to review (see below). The committee liked the idea of a ‘center of excellence’ for autism training, however worried about the availability of funding for it. **Mr. Figurski will review the list of recommendations and identify which agencies should be responsible for them.** Ms. Crandy asked all of the subcommittee members to look over the list and offer any other recommendations.

CONFIRM NEXT MEETING DATE:

The committee agreed to meet again on Tuesday, May 13, 2008 at 2:00pm to review their progress and continue with their discussion on the rights of adults with ASD, Evidence Based Treatments, Services that should be available across the lifespan to individuals with ASD, and committee assignments.

PUBLIC COMMENT:

Ms. Marson told the committee of a definition they are using for evidence-based health care and occupational therapy, “The integration of best research evidence with clinical expertise and patient values.” She said it seems to be a health care definition of best practice.

ADJOURNMENT:

With no other business to address Mr. Figurski moved to adjourn. Dr. Leaf seconded the motion and the meeting adjourned at 3:05 pm.

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 before 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 a 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 (Jacobson, Mulick & Green, 1996).
 - 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 known.**
- **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 childcare providers/daycare workers** will be aware of the early signs of ASD and where to refer parents if concerns develop.
- **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 children with Autistic Spectrum Disorders deserve:**
 - An effective therapy/treatment or instructional program which is or includes:
 - ✓ • 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

documentable 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.

- **Nevada adults with Autistic Spectrum Disorders deserve:**

- ✓ Professionals trained for caretaking across the lifespan – group home industry, nursing homes and/or natural supports.
- ✓ A culturally and linguistically competent workforce, which reflects the diversity of the individuals being served.
- ✓ Adults with ASD must receive multidisciplinary supports, therapies, vocational assistance, and other services to assist them in developing and maintaining life skills and successful employment.
- ✓ Appropriate wrap-around services for individuals with ASD and their families, using ASD trained respite and personal care providers.
- ✓ When out-of-home placement is necessary, provide families with a variety of options that are age appropriate, offer ASD trained staff, and are in an environment designed to meet the needs of the individuals served.
- ✓ Transition activities should include the collaboration and blending of service

resources well before the 21st birthday to support the expertise continuity in supporting an individual with Autism Spectrum Disorders; including schools, colleges, vocational programs, employment, supported employment providers, etc.

- ✓ Supported Employment/Day Program service providers will have specialized training in best practice supports and strategies to support individuals with autism spectrum disorders at work and in the community.
- ✓ Training in Social Skills
 - a) Ways of teaching social skills to include Social Stories, social skills groups, role playing, video modeling, peer-mediated instruction, pivotal response training, and computer programs that help with recognizing emotions or subtle non-verbal cues.
 - b) Social skills are not an end in themselves, but must lead to meaningful outcomes such as being effective and successful in relationships, school, work, leisure and independent living. Interventions should be evaluated in terms of approaching these outcomes (Volkmar, et al., 2005).

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.

“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)

Data on effectiveness and appropriateness for each individual must be considered when selecting, designing and implementing programs. Every program must include an evaluation component, which not only enables the team to make data-based decisions, but establishes a process for periodic review of the impact on the individual’s life.

Evidence-based practice involves the application of current research to the practice of treating others.

Although outcomes of research studies may evolve and change over time, together they result in current best practices for clinicians. These same standards should be applied to treating ASD. To determine if an approach is evidence-based, look for terms that include: data-based approaches, empirically supported treatment, best practices, empirically validated treatment, clinic and practice guidelines (Perry and Weiss, in press).

According to Green (1996), science uses direct observation that is objective and based on measurement that is systematically arranged. Science also requires repeated demonstration or replication of the research already conducted to measure its reliability. That is, the outcomes of one study can be repeated, supporting the reliability of research and results in the clinical use of a specific treatment.

Evidence-based treatments have established and demonstrated validity through the use of experimental rigor and replication.

To be able to have confidence in a researcher’s claim to a specific treatment requires rigor in the methods of how the research was conducted. To determine the level of rigor, one can examine the following elements and considerations: participant characteristics and how they are selected; targets that are considered and how meaningful and valid they are; measures used and what in fact they measure; how data is collected and how

objective or subjective it is; the soundness of experimental designs that are utilized in an attempt to show what is responsible for effects and to control for alternative variables; which results are reported (or excluded) and how honestly they are presented and depicted; and whether discussions seem to accurately reflect data obtained, avoid rampant speculation, and openly address the study's flaws and limitations. (Leaf, Taubman and McEachin, in press)

In order to draw conclusions about outcomes and their causes, data must come from **true experiments**. True experiments, or randomized field or controlled trials, test specific predictions and rule out alternative explanations. In an experiment, an investigator assigns subjects randomly to experimental and control groups, varies the apparent cause (the independent variable) and looks at the apparent effect (the dependent variable) while holding all other variables constant. Only true experiments can provide evidence of whether an instructional practice works or not. (*RMC Research Corporation under National Institute for Literacy Contract No. ED-00CO-009*)

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)

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.

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.

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.