

State of Nevada Autism Task Force
Best Practice Guidelines Subcommittee
MINUTES

Tuesday, May 13th, 2008
Teleconference

Members Present: Jan Crandy, Randy Figurski, Dr. Matt Tincani, Dr. Pat Ghezzi, Dr. Nancy Sylvanie, Erik Lovaas, Dr. Ron Leaf, Diane Branson, Debra Meinberg, and Assemblyman James Ohrenschall.

Members Absent: Cynthia McCray, Richard Thompson, Estleen Westby, Teri Vaughan, Valerie Soto, and Jennifer Van Tress.

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:

Approval of the minutes from the April 22, 2008 meeting of the Best Practice's subcommittee was postponed to the June 3rd meeting so that all of the members could have a chance to review them.

DEFINITION OF EVIDENCE-BASED PRACTICES:

Ms. Crandy circulated a definition of what is an evidenced based practice as revised by Dr. Tincani. The committee reviewed the document and agreed to remove "for children" in the recommendations to make them applicable to all individuals with Autism. Ms. Branson suggested revising the language in bulleted item #3 to make it more understandable to the lay-person. Dr. Tincani offered to change it to "Anecdotal evidence and opinion is excused in exchange for objective data." The committee then agreed to accept the revised version of this document.

DISCUSSION OF LIST OF RECOMMENDATIONS:

Ms. Crandy circulated a list of recommendations as revised by Mr. Figurski for the committee to review (see below). Mr. Lovaas suggested an appendix addition to item #4 concerning intensity. With the submission of item #7 by Dr. Leaf, the committee considered who would ultimately be responsible as an overseeing body. Ms. Crandy agreed to rewrite this item using the same language as Dr. Leaf, to identify which agency would be responsible for the oversight. After further discussion, it was suggested this item be rolled into a bullet under item #11. It was also suggested item #8 be amended to include the suggestion that the University of Nevada system be funded to build programs that support and produce more Applied Behavior Analyst graduates.

DEFINING BEST PRACTICE'S FOR ADULTS:

Dr. Sylvanie circulated a list of rights and services for the committee to consider that should be available for adults living with Autism in Nevada. Mr. Lovaas agreed to assist Ms. Crandy in reorganizing these so that Ms. Crandy can resend them out for committee review before their next meeting.

CONFIRM NEXT MEETING DATE:

The committee agreed to meet again on Tuesday, June 3, 2008 at 2:00pm to review their progress and finalize their recommendations to Nevada Autism Task Force. Ms. Crandy expressed concern the committee has not looked at what is currently available in the state. Mr. Figurski suggested working backwards from the committee's recommendations and what the findings would be, then sighting the sources.

PUBLIC COMMENT:

There was none.

ADJOURNMENT:

With no other business to address the meeting adjourned at 2:50pm.

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 Children 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)

III. Characteristics of Evidence-Based Programs for Children with Autism

- Evidence-based programs for children 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 parsimonious interpretation 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.

BULLETS FOR CONSIDERATION- PROMOTING - ADULT RIGHTS & SERVICES

Rights to an advocate for educational services

Rights of services for life--- the right to life long care

Rights of a comprehensive care plan-HEALTH AND EDUCATION

Rights of assistance with the application and process to obtain government benefits

Rights of Respite care

Rights of Daily living skills training

Rights of Independent living and group living center living

Rights to a 24 hour crisis/ help hotline

Rights of state Psychological/ counseling

Rights and access to an Autism Resource Center

Rights of Self Advocacy or to an advocate

Rights to a state Support group

Rights of Access to a Loan closet- ----equipment, etc.

Rights to an Assigned Guardian or Professional Trustee

Rights to obtain insurance (health and life)

Rights to a state appointed special needs alliance organization

Rights to a state appointed financial service provider or special needs alliance planner

Rights to a special needs tax free trust-(special needs trust)

Rights to a Supplement Needs trust

Rights to a parent-guardian inventory

Rights to an alternate expert/s

Rights to an educational advocate/s

Rights to a social service coordinator

Rights to a job coach/supported employment

Right to receive training, co-worker support, and assistive technology.

Rights to receive transportation

Rights to access a personal care attendant

Rights of a money manager

Rights of recreation activity

Rights of assistance with self -care

Rights of receiving routine medical care

Rights of comprehensive evaluations and follow ups –behavior and medical

Rights of an assessment for vocational transition

Rights of a behavioral assessment and progress report to accentuate vocational strengths

Rights of a functional skills inventory to list and emphasize strengths

Rights to community inclusion

Rights of clinical services for the following:

- a. Autism testing
- b. Abuse -prevention group services/participation access
- c. Dentistry-checkups and services
- d. Neurological exam/evals
- e. Occupational Therapy/evals/training
- f. Podiatry/eval
- g. Relationship counseling
- h. Psychiatric and/or psychological/services
- i. Physical Therapy
- j. Counseling/
- k. Speech and language therapy/training
- l. Health and safety training
- m. Yearly -medical physical
- n. Blood tests/screens
- o. DNA tests/screens
- p. Behavior therapy /training

- q. Social /Emotional/Relationship/ Skills training
 - r. Communication skills Training
 - s. Computer/technology training
 - t. Other- functional curriculum/educational training/American Sign language and / health issues /educational training / and/or other service or training deemed necessary.
 - u. Mentor service
 - v. Friendship training
 - w. Sensory training
 - x. Audiology/Auditory training
 - Y. Visual training
 - Z. Adapted physical education/recreation training
- **Also, any required equipment, service, assisted technology or augmentative service that is necessary for success and progress.

- Rights to have an ADULT 504 plan in the workplace
- Specific Rights of vocational services and employment:
- Adult community training/on job skills training
- Situational assessments/implementation with strategies, adaptations, modifications, and restructuring examples
- Functional resume written
- Vocational evaluations
- Maintenance team assistance
- Integrated work opportunities
- Rights to cross train
- Paid work experience opportunities.
- Rights to enter a free Life Center for adult learning
- Rights to an adult day habilitation center
- Rights of housing-low income
- Rights to all types of services, no age limit of when Autism was documented
- Rights of waiver services
- Rights to money reimbursement programs
- Rights to access bio-medical treatment
- Rights to access research scientific based treatment
- Rights to access any state adult foundation
- Rights to a 24 hour residential state facility
- Rights to access an Autism self help directory
- Rights to specialist to write a protective will
- Rights to a state I.D. protection system

Rights to a support group
Rights to celebrate success
Rights to volunteer

RIGHTS TO RECEIVE AN ADULT INDIVIDUALIZED LIFE PLAN!

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.

