

Ninth Annual Parent Conference: "Personal" & "Cozy"

It's hard to believe that another parent conference has come and gone! Although funding was uncertain, we were able to find alternative sources that made the conference a reality. We would like to thank Hilton/Perkins Program of Perkins School for the Blind; the U.S. Department of Education, Office of Special Education Programs (grant no. H326C990044-00); Nevada Parents Encouraging Parents; and the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind. Without the generosity of these organizations we would not have been able to hold this year's conference.

The conference was held at the University Inn, Reno on May 10th & 11th. We had a smaller

crowd than last year; however, all comments indicate that the conference was a huge success.

Fifteen parents and three service providers attended this year's



conference. The conference

included the following presentations:

- (1) Shared Experiences,
- (2) Dual Sensory Impairment: Is it Genetic?,
- (3) Experiencing my Child's World:

A Deafblind Simulation,

(4) Dancing with Miss Jenny,

(5) "Could you please tell my new

teacher?" Creating successful

transitions,

(6) "I have something to say!",

(7) My little brother, and

(8) "It's your turn!".

Comments from those

who attended the conference felt

that overall it was "A great joy &

pleasure" and "more useful to me

personally this time." Others

"gained something from every

session," and felt that "questions that I had were answered." Some participants liked the "small and cozy" group, and the group participation at this year's conference.

There were three comments to consider when planning next year's conference: having a later start time (conference started at 8:00 a.m.), having round tables for lunch so participants could visit in small groups, and to have participants bring photos to share during Marlyn's introduction circle.

Some suggested future conference topics included "assistive devices for older disabled children," "using the internet to access help and information," "adaptations for equipment as children get older," and "ways to properly move a child, etc., to make it easier on mom and dad."

We welcome all ideas for future conference sessions! It is our goal to make the conference as useful as possible. Please call or write to us if you have any suggestions for future presentations.

We are looking forward to holding our 10th parent conference next year! We hope to see you there!

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Federal Site Review Team Applauds NDSIP for being a “Well-organized and Efficient Project”

By MaryAnn Demchak, Project Director & Marty Elquist, Project Coordinator

The Nevada Dual Sensory Impairment Project is pleased to announce that we are finished with our federal site review!! NDSIP was very fortunate to have three excellent reviewers for our May 17 & 18 site review. Our review team consisted of June Downing, Marcia Fankhauser, and Carrie Masten.

Every state, region, or territory that received a grant from the US Department of Education, Office of Special Education, to provide technical assistance to parents and service providers of children who are deafblind, was required to have a federal site review during the October 1, 2000—September 31, 2001 fiscal year.

The purpose of the federal site review is three-fold. It provides information about the impact and outcomes of the state projects. This information is used to report to Congress. Secondly, the review team identifies if the individual projects need to change their activities in order to more effectively meet their objectives. Finally, the

site review team indicates if the project itself needs technical assistance.

Preparing for the federal site review was labor intensive, requiring several hours of staff time. We were very busy compiling project materials, evaluations, printing out reports from our various databases, sending out surveys, completing a self-evaluation, and setting up interviews between those involved with the project and the site reviewers. Although the preparation was a lot of work, we were very optimistic and confident that our performance would be positively evaluated.

The reviewers listed five major strengths and five recommendations for consideration. We would like to share all of their comments with you. The major strengths are in bold type. All comments that fell under the major strengths are bulleted underneath the item. If an item was recognized more than once, the number of times it was recognized is in parentheses.

It is important to note the site review team prefaced the recommendations for consideration by stating that all items would require additional funding.

Project Major Strengths

- 1. Production & dissemination of quality material that meets state’s needs and is utilized nationally (transition guide, Usher’s screening guide, Fact sheets) e.g., newsletters, fact sheets, transition guide, resource guide (20)**
- 2. Quality of project staff with regards to values, expertise, TA provision & accessibility, organizational skills (4)**

- Project has strong staff who work well together, well organized (6)
- MaryAnn’s inclusion background
- Research published on national level - MaryAnn (2)
- Marty’s know-how in doing this (website)

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For past editions of our newsletter, visit our website.

<http://www.unr.edu/unr/colleges/educ/ndsip>

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- Project coordinator provides strong technology component and data accessibility
- Synthesis of information for distribution, e.g. statistics (2)
Demographic information. Great documentation in colored graphics and published in newsletter (3)
- Evaluation, self-monitoring, record keeping (8)
Great job of synthesizing info. and extrapolating statistics
Constantly monitoring themselves; knowing where they are
On-going monitoring of project objectives and activities
Well evaluated activities
Very well organized and detailed
Monitored effectively
Evaluates all TA effectively and in timely manner
Database provides data on TA activities very rapidly for self-assessment
Follow-up data from TA given to participants
Project coordinator who is tech savvy to obtain feedback as needed
Carefully implemented and monitored management plan, very detailed and highly organized
Strong technology/data component!!!
Ready access to data
Project is very well organized, detailed, and implemented activities are carefully documented and monitored
- Accessible, well-respected staff, easy to work with (6)
- Project staff does an incredible amount of work with the staffing limits/budget limits they have (4)

And does it very well
Strong director & coordinator
Project has strong staff who work well together and accomplish great things with little FTE (full-time equivalent)

3. Excellent collaboration with a variety of different agencies and deserved respect/recognition by those in the state, e.g. Dept. of Ed., school districts, service providers, mutual respect (26)

- Project's excellent relationship with districts special education directors
- Director of Special Education felt this project was very effective at building capacity
- Relationships with service providers increases outreach
- Respected by other agencies
- Good collaboration with several agencies
- Close ties with State Dept. of Ed. (SIG grant)
- Good relationship with early intervention agencies
- NTAC, HKNC collaboration clear
- Project director is involved in numerous state committees
- Relationships with providers increases referrals
- Solid relationships with early education agencies
- Strong collaboration with many agencies including HKNC, NTAC, early intervention, State Dept. of Ed., University
- Cooperation with Centers of Excellence (old UAPs), use of distance learning, good support from University
- Strong collaboration and support from the university
- Strong collaboration with agencies and State Dept. of Ed. as well as national projects
- Systemic change: Project director is involved in numerous

state committees; excellent collaboration/relationship with Dept. of Ed. Membership in Nev. Administrative Code Revision work group resulted in a definition for deafblindness being included in the Nevada Administrative Code.

Working to train others to provide services
Great collaboration
Alternate assessment committee

4. Family centered approach is strong, project is responsive & meets families' needs in a variety of ways (Parent conference, informal parent to parent network, TA, advisory committee, web site)

- Parent input is solicited extensively
- TA request form sent to families and providers twice per year
- Great involvement from parents
- Project solicits (and values) their input
- Letters of invite to parents during TA
- Strong relationship with parents and accessibility
- Informational packets and resources
- Parent conference, newsletters, fact sheets
- Great involvement of parents, e.g., soliciting opinion (8)

5. Array of technical assistance as well as the quality of on-site, satellite, distance learning, lending equipment and library

- Web site, e.g., able to quickly pull off data, access (9)
- Fact sheets in Spanish as well as English (3)
- Dissemination of information – large, diverse groups of people (4)
- Good lending library and

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- equipment loan (5)
- Good newsletters
 - Family friendly newsletter
- Clear TA request form
- Toll-free number (1)
- Resource Guide (2)
- Technical assistance (8)
 - (Child specific, group training)
- Technical assistance action plans and follow up (5)
- Technical assistance includes parents (2)
- Technical assistance evaluated
- Child-centered TA & training (2)
- Recommendation forms on NCR paper so participants see follow-up data to be collected (2)
- Use of inclusion, best practices (3)
- Trainings are based on updated research and best practices (conferences, trainings, satellite) (7)
 - Trainings provided are based on current effective practices, updating library materials frequently, newsletter and fact sheets reflect current practices
 - TA provided is based on current best practices
 - Transition booklet promotes inclusion
 - Good relationship with Dept. of Ed. can help promote best practices
 - Project director's expertise in best practices; she publishes Value-based regarding quality of life issues, which promotes inclusive and service integration
 - Inclusion valued by staff
 - Staff expertise valued
- Parent conference (9)
 - Commitment & dedication to pulling it off with budget cuts
- Inclusion of providers in parent

conference

- Opportunities for individuals to request additional training/support, e.g., trainings, TA requests forms sent regularly (8)
- Good screening workshops (4)
- Contacts with nurses and other service providers

Although the comments about our Advisory Committee did not fall under one of our major strengths, the committee was praised for several reasons:

- Diverse, meets the state's needs
- Enthusiastic, parent membership
- Very involved
- Represents diverse geographic areas and roles with students
- Good parent representation
- An involved advisory committee

Please remember that the site review team prefaced the following recommendations for consideration by stating a need for additional funding.

Recommendations for Consideration

- 1. Explore ways to contract with a family member to provide special expertise to project**
- 2. Increase effort to promote systematic change in the state and ensure least restrictive environment and integrative service delivery for all students with deaf-blindness**
- 3. Explore partnering with others to hold a family retreat (i.e., camping or family outing) that includes siblings & child care (5)**
(Project comment: Although a family retreat is the preference of parents in other states, parents of children who are deafblind in Nevada have stated that they do not want a retreat at a camp with their families. Parents specifically stated that they prefer to stay in a hotel and attend conference

sessions that pertain to their children.)

- 4. Consider holding a statewide initiative specific to deaf-blind issues to build local capacities**
- 5. Consider increasing the representation of diverse culture on the advisory board (5)**

- Continue efforts to increase representation on Advisory Committee in regards to ethnicity and deafblindness (perhaps consider a representative from the blind/visually impaired or deaf/hard of hearing community if deafblind unavailable)

*(Project comment: Currently our Advisory Committee includes one member with a hearing impairment and another with a physical impairment. We do **not** feel comfortable asking our members to self-identify their racial/ethnic backgrounds for fear that this type of questioning might be offensive to someone. It is also important to note that the US Department of Education does not request this information.)*

We were very pleased that the site review team felt that some project materials and activities were of national significance! Here are the site reviewers' comments about the materials and activities that were awarded this status:

- Fact sheets are used by many other projects throughout the country
- Newsletters
- All written materials have the potential to be nationally significant
- Project director publishes articles based on current best practices in nationally distributed newsletters

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- Transition manual
Very family friendly
- State Dept. of Ed. takes no money but has funds flow directly to project at University
- Project director publishes a lot in the field (inclusion, best practices)
- Fact sheets, Transition Booklet, Usher Booklet: Potential to be used nationally if not already

The review team left us with this final comment, "We appreciate the opportunity to review a well-organized and efficient project. We would like to commend the project for its impact on a national basis, such as its Fact Sheets, especially those in Spanish, its Transition Manual, and the Project Director's published work in this area."

Overall we were extremely pleased about the outcome of the site review. Thank you to everyone who completed the site review survey, participated in the phone interviews, or agreed to meet for lunch. Your input for the site review team was invaluable. We look forward to continuing serving Nevada parents and service providers of children who are deafblind!

Upcoming Conferences/Trainings

Workshop on Pre-symbolic Communication & Tangible Symbol Systems

Presented by: Charity Rowland, Ph.D., and Philip Schweigert, M.Ed.

Learn how to help nonverbal children with severe disabilities communication their needs to care givers and teachers. This two-day workshop, designed for professionals & parents, addresses Pre-symbolic Communication and Tangible Symbol Systems.

July 9-10, 8:30 a.m. – 5:00 p.m.
Mt. Bachelor Village Resort
Bend, OR
Registration deadline: June 15

For more information
 Alexandra Dorinson, 1-800-410-7069, Ext. 102
 Email dorinson@ohsu.edu
 Website: www.designtolearn.com

TASH Teleconferences

These sessions are conferences which take place via the telephone. Registrants will be sent an 800 number & a passcode to access the seminar for which they are registered. Handouts will be sent out in advance.

Sessions

- Mon., June 11, 1:00-2:30 (EST): **Functional Assessment**
 - Tues., June 19, 1:00-2:30 (EST): **Designing Positive Behavioral Intervention**
 - Fri., June 22, 1:00-2:30 (EST): **School-Wide Behavior Support Plans**
 - Wed., June 13, 1:00-2:30 (EST): **Post Secondary Education: A Choice for Everyone**
 - Tues., June 19, 2:00-3:30 (EST): **Affordable, Accessible, & Integrated Housing**
- For more information: Denise Marshall • dmarsh@tash.org • 410-828-8274 ext. 103**

"You Don't Have to Live with It: Saliva Overflow"

RESNA Annual Conference
 June 22-June 26
 John Ascuaga's Nugget
 Sparks, NV
 For more information:
 RESNA
 703-524-6686 (v)
 703-524-6639 (tty)
 703-524-6630 (fax)

Website on saliva overflow:
ih.s.airweb.net

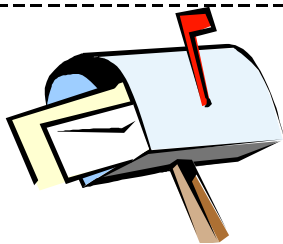


Shorter Web Address Same Site!!

<http://www.unr.edu/educ/ndsip>

Please change your bookmarks!

The University of Nevada, Reno has a new web server, and we have a new web address:
www.unr.edu/colleges/educ/ndsip



I enjoy your newsletter, and I know someone who would benefit from receiving future issues. I have entered their address below.

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New Lending Library Resources

Guides

Rowland, C., & Schweigert, P. (1999). It's always time to learn: An environmental inventory to help teachers design learning activities for children who are deafblind. Portland, OR: Oregon Health Sciences University.

Time to Learn is an environmental inventory designed for teachers of children who are deafblind or who have other severe or multiple disabilities. The inventory is used to identify and create opportunities for active participation and steady learning in everyday classroom activities. The 55-page booklet contains both the User's Guide and the Inventory.

Riggio, M. & McLetchie, B. A. B. (2001). Competencies for paraprofessionals working with learners who are deafblind in early intervention and educational settings. Watertown, MA: Perkins

School for the Blind.

This guide addresses the knowledge and skills that a paraprofessional must have in order to assist in implementing quality programs and in enhancing the quality of life for learners who are deafblind.

Manuals

EP Foundation for Education (2001). Universal newborn screening. Oradell, NJ: Author.

This monograph includes a history of newborn screening in the US, outlines the various methods to testing, and describes the 30+ conditions that now can be detected and treated.

Special Editions

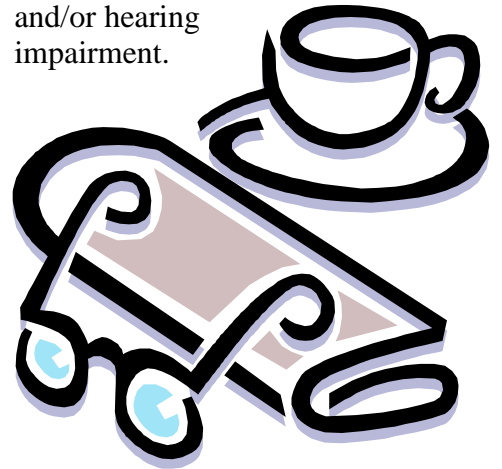
Shinnar, S., & Spivey, J. C. (Eds.) (2000). Contemporary issues in epilepsy: What families need to know about childhood seizures. Exceptional Parent Special Report on Epilepsy. Oradell, NJ: Psy-Ed Corporation.
This special edition is a collection of

articles that discusses the prognosis of epilepsy, genetics, the struggle, first aid, and talking about the future. This issue attempts to use common English instead of medical jargon and contains a glossary of commonly used terms associated with epilepsy.

Videos

Simulations of Different Types of Hearing & Vision Loss (9:21)

This video demonstrates what it is like to have different types and degrees of vision and hearing loss. The video gives a nice introduction to what it is like to have a vision and/or hearing impairment.



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and visual impairments
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