



Newsletter

Vol. 13, No. 1

September 2002

The Nevada Dual Sensory Impairment Project aims to enhance the educational services provided to all children and youth, birth through 21 years, who have dual sensory impairments by providing technical assistance to families and involved agencies.

Who Are "Our Kids?" A 10 Year Project Analysis

Each spring the Nevada Dual Sensory Impairment Project is required to submit a report to the US Department of Education, Office of Special Education regarding the children involved with our project. This report is a "snap shot" of our children on December 1st of each year and consists of the information that we are mandated to collect. In this newsletter we begin a discussion of our child count over the last 10 years. We begin by looking at the breakdown of ages of our children, the major cause of disability, and the degree of vision and hearing loss. In the December newsletter, we will review the disability categories under which our children are reported by the school districts

and early intervention agencies, the other impairments our children have, as well as where our children go to school and live.

Number of Children. Over the past 11 years our project has experienced

tremendous growth in the number of children identified as having both vision and hearing impairments. Figure 1 shows that our project started in 1990 with only 26 children. As the population of the state has increased, so has the

number of our children. On the December 1, 2001 child count we had 98 children involved with our project. (Please note that our mandated reporting guidelines changed so drastically after 1990 that only Figure 1 includes data from that year.)

The remaining reporting areas are discussed in terms of

"Our Kids" continued on page 2

Number of Children by Year 1990-2001

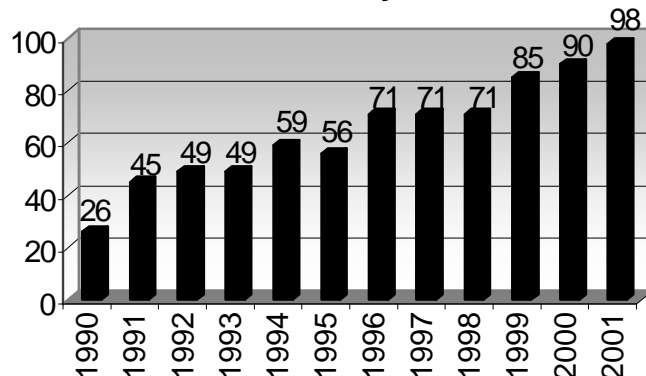


Figure 1

Ages of Our Children 1991-2001

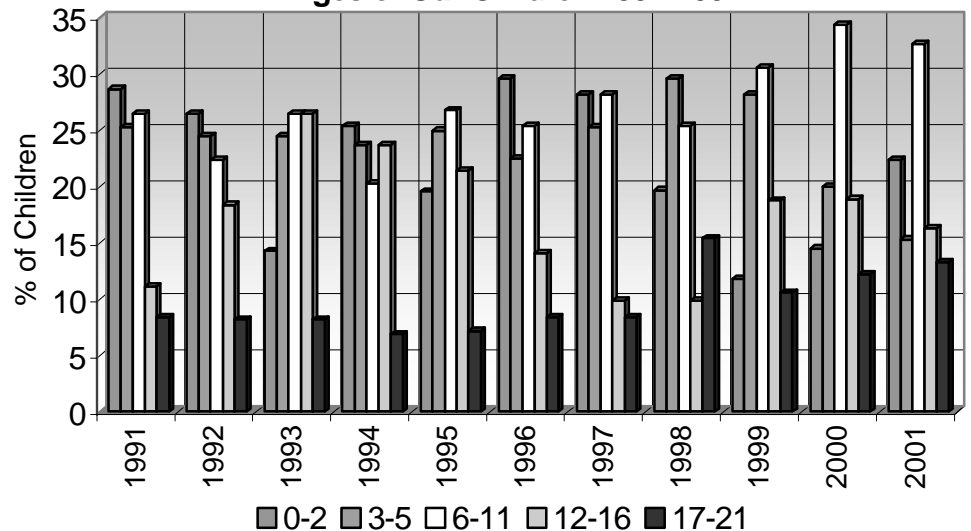


Figure 2

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percentages and not numbers. Due to the project growing by over 50% since 1991, discussing the areas in terms of numbers would potentially be misleading.

How Old Are Our Kids? Figure 2 (page 1) shows the break down of our children's ages over the past 10 years.

During the early years of our project, we focused awareness efforts on the developmental specialists of Nevada's early intervention agencies as well as the early childhood special education teachers of the school districts. The awareness of the impact of dual sensory impairments on the development of infants, toddlers, and preschoolers resulted in numerous referrals to our project of children in these age ranges. As a result, the "birth through 2 years" and "3 years through 5 years" groupings are consistently some of the highest percentages. The natural process of "aging" results in steady or increasing numbers in the "6 years through 11 years" and the "12 years through 16 years" categories. The

"17 years through 21 years" grouping is consistently the lowest category. However, many of our children have graduated at about 18 years of age and so it is not surprising that we see a large drop off of percentage of children in this age group. There have been a few times in the history of the project when professionals have taken a special interest in

vision and hearing to us.

What Is the Cause of Disability for Our Kids? The project is required to report the primary cause, or etiology, of the child's disability. Figure 3 shows that prenatal complications have been the most frequent cause of disability for our children over the past 10 years. What are "pre-natal complications?" Included are congenital infections during the pregnancy (e.g., rubella, syphilis, toxoplasmosis, CMV), the mother's abuse of drugs or alcohol during the pregnancy, hydrocephaly, and microcephaly. For our children, the most common prenatal causes are hydrocephaly and microcephaly. (Please see page 4 for a discussion of

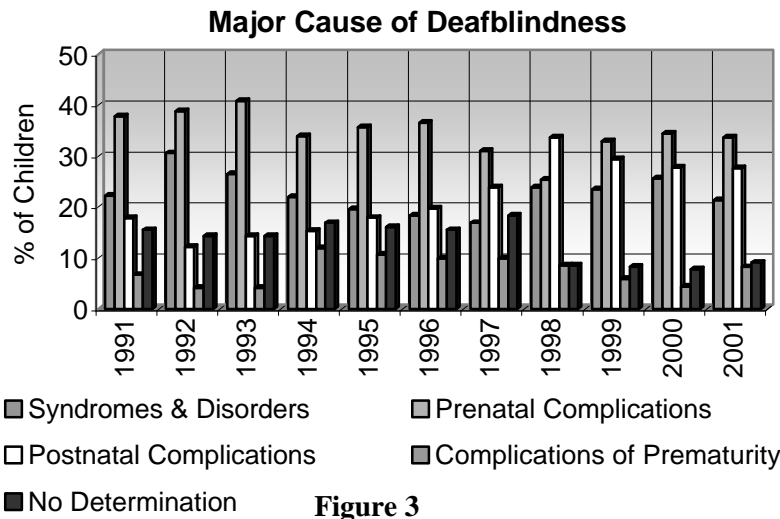


Figure 3

ensuring children are referred to us. In the 1999-2000 school year a nurse at a special school for students with significant disabilities reviewed each child's file to determine eligibility. Similarly, during the 2000-01 school year a vision specialist at one of the early intervention agencies made sure that her colleagues were referring children with impairments in both

hydrocephaly.)

What are "post-natal complications?" This category includes causes such as asphyxia, trauma to the eye and ear, infections (e.g., encephalitis, meningitis), severe head injury and others. On our child count the most commonly

"Our Kids" continued on page 3



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For past editions of our newsletter, visit our website.

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



This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education.

reported post-natal cause is asphyxia resulting from a variety of incidents such as near-drowning, surgery complications, and birth trauma.

"Syndromes and disorders" consist of 57 specific syndromes or disorders that the child inherits or that result from chromosomal abnormalities. All of the syndromes and disorders listed in our referral packet have an increased likelihood of the child having both vision and hearing impairments. On our child count we have 12 children who have 9 of these listed syndromes. It is important to note that the list is not an exhaustive one and that numerous other syndromes and disorders that are associated with vision and hearing impairments exist. We have another 10 children who have some of these other syndromes (e.g., 18q syndrome, Fraser syndrome).

The last specific category pertains solely to complications of prematurity. Although many children are born prematurely and have no lasting complications, other children have a variety of complications that can include motor impairments, seizure disorders, cognitive impairments, as well as vision and hearing impairments.

The final option for the cause of disability is "No Determination of Etiology," which is a fancy way of saying the cause is unknown. Since 1998 the percentage of children in this category has dropped dramatically.

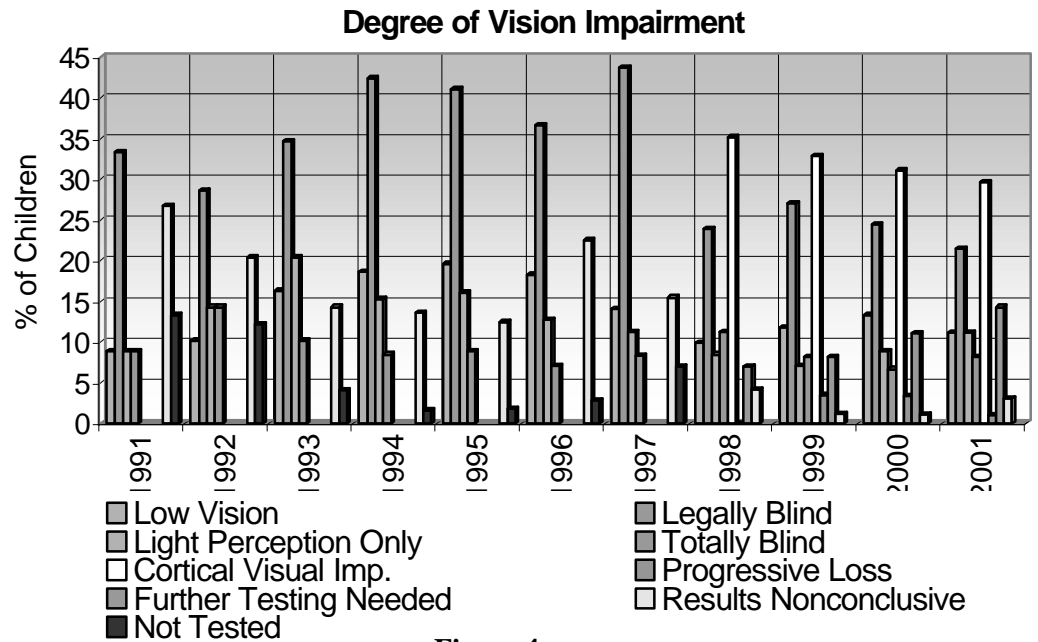


Figure 4

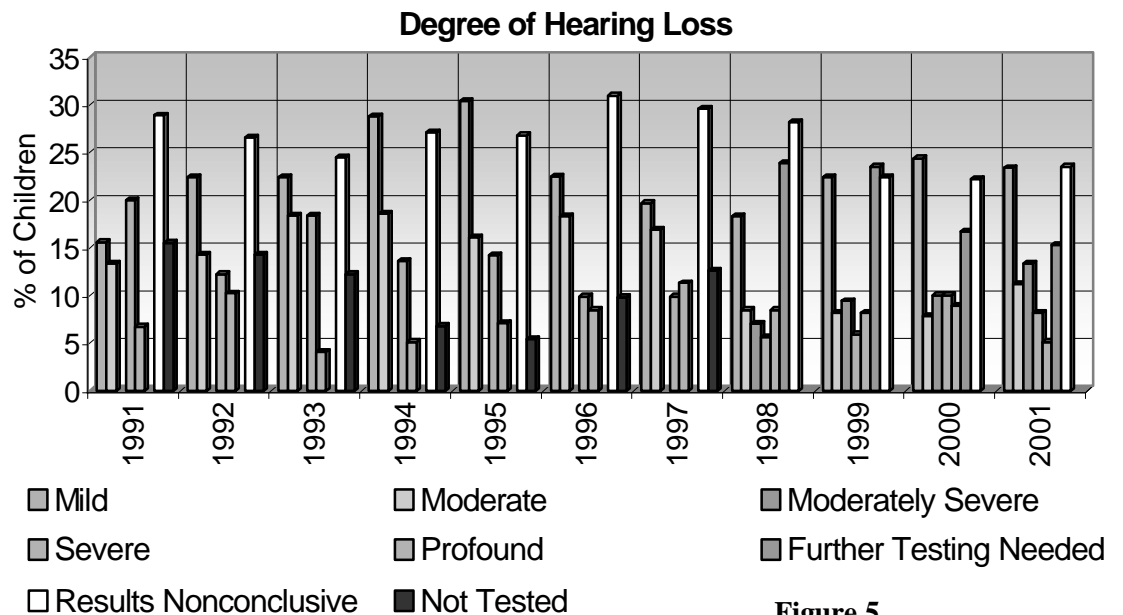


Figure 5

What About Our Kids' Degree of Vision Loss? In terms of vision, the majority of our children are currently identified as having cortical visual impairment (CVI) (Figure 4, page 3). CVI has been a separate category under degree of vision loss only since 1998. Prior to that time, the majority of our children were identified as "legally blind" (visual acuity of 20/200 or less or a visual field of less than 20 degrees). Since 1998 "legally blind" is the second most frequent category of vision

Central Auditory Processing Disorder

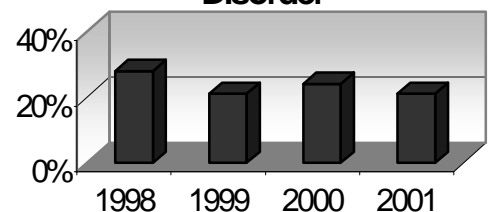


Figure 6

impairment. In 1998 "progressive vision loss" was added; but very few children have been identified in this area (three in 1999 & 2000 and one in

Focus on Hydrocephalus

By: MaryAnn Demchak, Project Director and Marty Elquist, Project Coordinator

Welcome to our new column *Focus on*. This will be a regular column in our quarterly newsletters and will highlight a different syndrome, disorder or condition related to vision and hearing loss in each edition.

What is hydrocephalus?

A condition characterized by an abnormal accumulation of cerebrospinal fluid within the ventricles of the brain. Normally, cerebrospinal fluid travels downward from the ventricles of the brain to the base of the brain and spinal cord and then over the surface of the brain where the fluid is reabsorbed. However, in hydrocephalus the flow of the fluid is often blocked and a damming effect occurs. Sometimes the cause is the production of too much cerebrospinal fluid. The ventricles swell to accommodate the excess fluid and the brain becomes compressed.

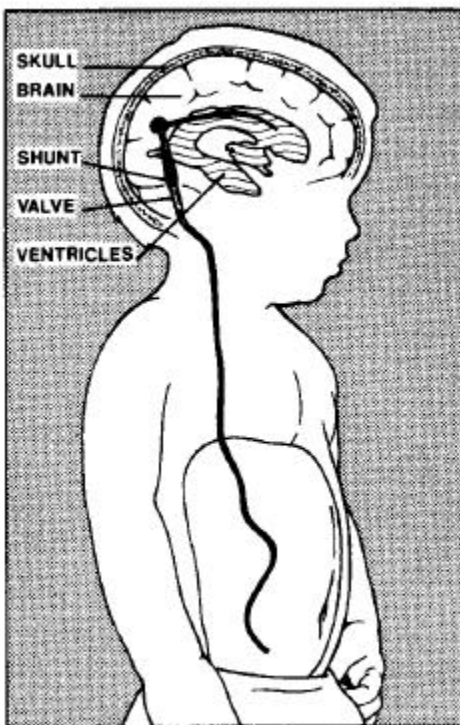
What causes hydrocephalus?

Hydrocephalus is not hereditary. In many cases it is congenital (i.e., it originates prior to birth) and can be associated with other conditions such as spina bifida. Hydrocephalus can also be *acquired*, where the condition is the result of infection (e.g., meningitis--an infection of the coverings of the brain), head trauma, brain tumors, cysts, or a hemorrhage in the ventricles of the brain. Sometimes the cause of hydrocephalus is unknown.

How is hydrocephalus treated?

Children with hydrocephalus are usually treated with medication or the surgical placement of a permanent bypass, called a shunt. This is usually a ventriculo-peritoneal shunt. In this procedure a tube is inserted into the ventricles of the brain. This tube is connected to a one-way valve that allows the

cerebrospinal fluid to flow out of the brain. The valve is connected to flexible tubing that is threaded under the skin into the abdominal cavity. The cerebrospinal fluid flows from the brain into the tube, through the valve, and down the tubing into the abdominal cavity. There the body reabsorbs the fluid. (In some rare cases the tubing is threaded into the heart rather than the abdominal cavity.)



Ventriculo-peritoneal Shunt

Can the shunt ever malfunction?

Yes

What are the symptoms of a malfunctioning shunt?

- Increase in head size
- Fever
- Behavioral changes--extreme irritability or fussiness
- Increase in sleepiness or drowsiness
- Seizures
- Diminished reaction to the environment or lethargy
- Forceful vomiting

- Swelling or redness of the skin in the area of the shunt
- Headaches
- Eye muscle weakness--"Setting Sun" eyes (iris is only partially visible due to a downward gaze)

What are the effects of hydrocephalus?

Left untreated hydrocephalus can result in a faster than normal increase in head size. The increase in head size and pressure on the brain can result in loss of vision, recurrent headaches, back & neck pain, a progressive decline in balance & coordination, and a decline in cognitive abilities.

Web resources on hydrocephalus

Hydrocephalus Foundation
<http://www.hydrocephalus.org>

Hydrocephalus Facts & Links
<http://members.nova.org/~twinkee/HydroLinks.htm>

Steve's Hydrocephalus Page
<http://web.syr.edu/~sndrake/hyd1.htm>

775-784-6471 877-621-5042
In the Reno area Toll-free in Nevada

I want to find out more about...

If you would like any information on a particular syndrome, disorder, or other cause associated with vision & hearing loss, let us know and we will highlight it in a future newsletter!

Call or use the contact information on page 2 to submit the below information:

NAME: _____

ADDRESS: _____

TOPIC: _____

Self-Determination. A recap of the NFADB/NTAC Parent Conference

By: Fred Woodard, father and deafblind advocate

Hello All! I just want to share a little information that I gained from the August 2002 Parent Conference that was held in Kansas City. The conference was sponsored by the National Family Association for the Deaf-Blind (NFADB) and the National Technical Assistance Consortium (NTAC) for Children and Young Adults who are Deafblind.

The main presenter at the conference was Dr. Brian Abery, Project Director, Institute of Community Integration, University of Minnesota. The theme of the conference was *"BEING SELF DETERMINED: WHAT DOES IT TAKE? Skills + Knowledge + Attitude + Opportunity"*

Dr. Abery stated that self-determination is necessary for the development of one's identity and is a basic quality of life component. Self-determination includes making decisions about anything from what a person wears or eats, to where they live or work. He also stressed the importance of providing support for individuals striving to be self-determined.

It was emphasized that ALL individuals want to feel they are in control of their lives. When we are not, it affects our overall attitude. This applies to individuals who are deafblind, who have other disabilities, as well as those who do not have disabilities.

Being self-determined requires skills + attitudes + knowledge + opportunity. It might mean that we as parents, or support people, may have to invest additional time teaching. It could mean that the roles of individuals in the family might change and we might have to re-negotiate rules and limits. We might need to think

outside the box and be more creative, or we might even have to allow a person to take risks and possibly experience failure. These can be frightening concepts. Nonetheless, these changes are important to allow those we love, and support, to exercise self-determination.

There are many positive results from being self-determined. These results can include improved learning, increased responsibility,



higher self-esteem and greater self-awareness. The individuals may also experience greater community participation and greater control over their lives. Overall, quality of life is enhanced.

There are also benefits for the families when individuals are self-determined. Generally challenging behaviors are diminished. It seems as if parenting becomes more satisfying as parents move from a caregiving role to a supporting role. This new role leads to shared decision making and less need to guess about the individuals' preferences. Being self-determined does not mean absolute independence. People who are highly

self-determined realize they need others in their lives.

It was brought up repeatedly that families must never be forgotten. Families are the catalyst to help individuals learn to make informed decisions and increase their self-determination. Families are the primary source for individuals to develop the skills to be self-determined. Family members provide more love, nurturing, and understanding than paid staff could hope to supply.

Families provide individuals opportunities for experimentation with making decisions and choices at an early age. We should encourage individuals to make choices and decisions and positively reinforce attempts at being self-determined. We as parents should also support the choices made, even if it is not one we would have made for ourselves. Simple choices should be nurtured into larger, more complex decisions. Ultimately, individuals should learn to take responsibility for their choices and know that their selections will not only affect them, but also others who support them.

Families can help individuals set realistic goals and attain them. Parents have the ultimate responsibility for their children's well being. However, they need to allow their children the opportunity to expand their horizons and make decisions for themselves. Parents should also realize that their children may sometimes make "poor choices" and need to understand that this can be a positive growing experience.

The conference in Kansas City was a wonderful opportunity to learn new concepts. I hope I can use this information to increase the self-determination of people with disabilities.

"Our Kids" continued from page 3

2002). However, this category is an important addition due to the implications of having a progressive loss. When the project first started, we had the option of reporting our children as "not tested." In 1998 this reported option was eliminated.

Combining the percentage of children in the categories of "tested, results nonconclusive" and "further testing needed" show that we have many children who are difficult to test and for whom it is difficult to obtain definitive results.

Degree of Hearing Loss and Our Kids. In terms of hearing loss (Figure 5, page 3), "tested results nonconclusive" has been a major category for the past 10 years. Similar to the vision area, we have a many children for whom it is difficult to obtain definitive results when hearing is tested. Over the 10 years of our analysis, the most consistently used category for degree of hearing loss of our children is a mild impairment (defined as 26-40 decibels). The remaining categories of hearing loss are defined as (a) moderate loss (41-55 decibels), (b) moderate severe loss (56-70 decibels), (c) severe loss (71-90 decibels), and (d) profound loss (greater than 90 decibels). In 1998 we began to collect data on whether or not our children had a central auditory processing disorder. Figure 6 (page 3) shows that 1 out of 5 our children are currently identified as having a central auditory processing disorder.

Why Should Children Be Referred to Our Project? Many of you who are familiar with our project know that our purpose is not simply to identify children with impairments in both vision and hearing. We provide these services to parents and teachers of identified children:

- ◆ assistance in identification of individuals with dual sensory impairment,
- ◆ provision of on-site technical assistance (e.g., consultants, inservice workshops, program review) to families as well as educational & early intervention providers,
- ◆ maintenance of a lending library,
- ◆ quarterly newsletter,
- ◆ parent access to a parent-to-parent network,
- ◆ teacher access to a teacher-to-teacher network,
- ◆ a yearly parent conference.

Technical assistance is provided throughout Nevada in the child's home, school, or early intervention agency. All technical assistance is provided at no cost to families, school districts, early intervention agencies, and others who provide services to children with dual sensory impairments.

Referrals to the project can be made by parents as well as educational, medical, and social service agencies. If you would like to refer someone to the project, please call (775) 784-6471 in the Reno area, or 877-621-5042 toll-free in Nevada, for a referral packet, or visit our website at www.unr.edu/educ/ndsip to submit a referral online.

Upcoming Conferences

13th Deafblind International

World Conference on Deafblindness

Sponsored by: The Canadian Deafblind and Rubella Association & Deafblind International

August 5-10, 2003 • Mississauga, Ontario Canada

For more information: 1658-4th Avenue West, Owen Sound, Ontario Canada, N4K 4X4

E-mail: mail@dbconferencecanada.com,

Website: www.dbconferencecanada.com,

Phone: (519) 372-2068

Fax: (519) 372-0312

PECS--Picture Exchange Communication System

Sponsored by: Pyramid Educational Consultants

October 17 & 18, 2002 • Reno, NV

For more information: 2226 West Place, Ste. 1, Newark, DE 19711

Website: www.pecs.com

Phone: (888) 732-7462

Great IDEAs about Special Education Reform

From The Committee on Education and the Workforce
Website: <http://edworkforce.house.gov/issues/107th/education/idea/ideacomments/index.htm>

Adapted from original message by Rep. Michael Castle (R-DE)

This year, Congress is scheduled to review America's special education law, the Individuals with Disabilities Education Act (IDEA), as the next step in President Bush's effort to improve education for all children. The Education & Workforce Committee needs your help to strengthen IDEA and to ensure that no child is left behind.

The committee is interested to hear suggestions from parents and professionals about how IDEA should be changed and why. To help guide your comments, some of the key topics that the members are interested in learning more about include:

- Increasing accountability and improving education results for students with disabilities.
- Reducing the paperwork burden.
- Improving early intervention strategies.
- Reducing overidentification/misidentification of nondisabled children, including minority youth.
- Encouraging innovative approaches to parental involvement and parental choice.
- Supporting general education and special education teachers.
- Rewarding innovation and improved education results.
- Restoring trust and reducing litigation.
- Ensuring school safety.
- Reforming special education finance & funding.

Want to voice your opinion? Go to:

<http://edworkforce.house.gov/issues/107th/education/idea/ideacomments/index.htm>



New Lending Library Resources



Guides

Blaha, R. (1999). *Calendars for students with multiple disabilities including deafblindness*. Austin, TX: Texas School for the Blind and Visually Impaired.

This guide was developed for staff and families of students with multiple impairments including deafblindness. The purpose of the guide is to communicate the benefits of calendar systems, provide information for calendar programming to be based on students' current needs and skills, and provide information on the continuum of calendars so that staff and families are able to make decisions regarding expanding student's skills.

Material ID #: 530.100

Monmouth, OR: The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind.

People with combined vision and hearing loss may have additional physical or cognitive disabilities. Self-determination is an appropriate goal for these individuals. With an appropriate level of support, people with significant disabilities can lead self-determined lives. This paper explores how self-determination applies to individual who are deaf-blind & how it affects families, educational programming, and service delivery.

Material ID #: 480.103

receptive communication (Fact Sheet).

Reno, NV: University of Nevada, Nevada Dual Sensory Impairment Project.

Material ID #: 2900.44

Demchak, M., Rickard, C., & Elquist, M. (July 2002). *Providing cues to enhance expressive communication*(Fact Sheet). Reno, NV: University of Nevada, Nevada Dual Sensory Impairment Project.

Material ID #: 2900.45

Demchak, M., Rickard, C., & Elquist, M. (July 2002). *Cortical visual impairment* (Fact Sheet). Reno, NV: University of Nevada, Nevada Dual Sensory Impairment Project.

Material ID #: 2900.46

Articles

Kaderavek, J. N., & Pakulski, L. A. (2002). Minimal hearing loss is not minimal. *Teaching Exceptional Children*, 34(6), 14-18.

This is an excellent article that discusses the implication of having a minimal hearing loss (MHL). A MHL is a loss between 16 and 25 dB and significantly affects a child's ability to learn language and succeed in school. This article explains why children with MHL are at a distinct disadvantage in many classrooms and explains what we can do about it!

Materials ID #: 1440.110

NTAC Briefing Paper

Morgan, S., Bixler, E., McNamara, J. (2002). *Self-determination for children and young adults who are deaf-blind*.

NDSIP Fact Sheets

Demchak, M., Rickard, C., & Elquist, M. (July 2002). *Providing cues to enhance*

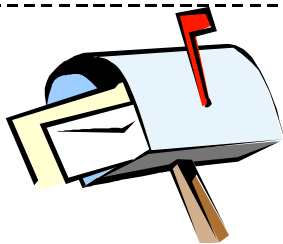
Help us help you!

We aim to make our lending library as useful as possible! If you know of any materials specific to vision impairments, hearing impairments, dual sensory impairments, materials for parents, early intervention, orientation & mobility, transition, positive behavior support, alternative/augmentative communication, etc. that would enhance our lending library, we welcome your suggestions! Especially recommendations for those materials in Spanish!! If you have found a particular resource to be useful, we would love to hear about it! Please call, mail (electronic or standard), or fax your suggestions (author & title) to:

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

I've moved! Please send future issues of your newsletter to my new address below.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

**Return to: Marty Elquist Department of Curriculum & Instruction/282
University of Nevada, Reno Reno, NV 89557**

E-Mail Discussion Groups & On-line Bulletin Boards

The Internet has enabled us to share information from all parts of the country and the globe! For those who are deaf-blind, their family members, and professionals who serve them, the Internet has become a wonderful place to share information and to talk to each other about many different issues. One great way to share information is through the use of on-line bulletin boards and e-mail discussion groups. Here is a partial list of what is currently available:

Nevada Dual Sensory Impairment Project Bulletin Boards-

Parents and Professionals can subscribe to notification e-mails every time there is a new message placed on the bulletin boards. The bulletin boards can be used to offer expertise or to request information from other parents and/or professionals. Subscribe and post messages at www.unr.edu/educ/ndsip/pnet.html (parent network) or www.unr.edu/educ/ndsip/tnet.html (teachers & paraprofessionals).

National Family Association for Deaf-Blind. This is a e-mail discussion group where messages will be directly sent to subscribers' e-mail inbox without being posted on a website. This list is for parents and families of those who are deaf-blind. To subscribe, just send a blank e-mail to: nfadb@mailservice.cpd.usu.edu. Make sure you type "subscribe" in the subject line.

Deaf-Blind Education Mailing List (DBED-L). If you would like to share information and ask questions about deaf-blind education, this mailing list is for you. To subscribe, simply send an e-mail message to listserv@tr.wou.edu. In the body of the e-mail message type the following text: SUBSCRIBE DBEDL *your first name, your last name*. For example, John Doe's text body would read: SUBSCRIBE DBEDL John Doe.

DB Teens. To subscribe to this e-mail discussion group, you must contact Randy Klumph (klumphr@wou.edu) for more information. This group is only for teens and young adults.

Website

In The
Spotlight

American Foundation for the Blind
CareerConnect™

www.afb.org/careerconnect

AFB CareerConnect is an interactive website where people with visual impairments can explore the world of work. The latest resource enables job seekers who are blind or visually impaired to learn about specific careers, connect with prospective mentors who are visually impaired and working in a particular field of interest, create a resume, obtain valuable interviewing techniques, learn about the latest technologies in use at various worksites, and more. At www.afb.org/careerconnect your clients can learn about a wide range of careers with the help of more than 1,500 mentors in our fully accessible database.

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