## The Silent Dark

### Nan Rosen

The moon's a distant speck
The stars are out of sight,
But I have found ways
by faith and cane
to navigate the night.

The sun is dimmer now
and colors fade away
into a hazy distance
without form where
darkness always stays.

Birdsong is distant now.
Music sounds unclear
and voices softly strained.
I know the silent dark
is drawing near.

And yet I find new meaning
in all things I can feel —
In taste and pain
and friendship's touch
that only contact can make real.

I notice things
that with sight I did not see —
The smell of rain,
the rough and soft of
bark and moss upon a tree.
I feel the grass beneath my feet.
The sun, unseen, shines warm upon my face.
The wind's caress the talking
touch of nature's hand.

I find joy in tastes and smells of holidays
when friends and family come around.
My world expands in written words and signs.
Communications kiss beneath my hand,
break through the silent darkness of my life
to bring the most precious gift of all,
the gift of hope and love.

*Nan Rosen lives in Colorado and often writes poetry. She is a handweaver, trying to keep up the craft as her vision decreases. She also creates art using polymer clay. Previously, Nan was a member of the American Association of the Deaf-Blind (AADB) Board of Directors during the 1980s. During that time, she was co-chair of the AADB convention when it was held at the University of Northern Colorado in Greeley. Nan also edited* The Deaf-Blind American *for several years. The poem* The Silent Dark *was written for friends on the Deafblnd Mailing List, an e-mail discussion group.*

## In This Issue

# Resonance Boards

David Brown
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The idea of using hollow resonating boxes or platforms to help deaf people perceive sounds as vibrations has been known for centuries (Lane, 1984). You may have seen teachers in programs for deaf students stamp their feet on wooden classroom floors to get the students' attention. One of the leading classical musicians in the UK, Evelyn Glennie, is a percussionist who is profoundly deaf and partly "feels" the music through the wooden platforms on which she stands to perform (*The Evelyn Glennie Home Page*). This idea was introduced into the world of visual impairment and blindness when Lilli Nielsen began to promote the use of resonance boards by children who had visual impairments and additional difficulties (Nielsen, 1992). Then, in the later 1980s, people involved with children who are deaf-blind took up the idea, and it is now possible to find these simple but useful pieces of equipment in all kinds of programs and in homes (Johnson, Griffin-Shirley, & Koenig, 2000). Every baby and infant should have access to a resonance board as part of their collection of toys and equipment since these boards offer great and exciting opportunities.

## How Do You Make a Resonance Board?

There is scope for creativity and variety in making a board, but the basic design is simple and requires only rudimentary skills in carpentry. To make a board you will need the following materials:

◆ *A square piece of plywood at least 1/8 of an inch thick.* The thickness may vary depending upon who is going to be getting on the board. Remember that if the board is too thin it will split when an adult kneels on it, and if it is too thick it will not resonate very well. I suggest that you stand in a timber shop and hold sheets of plywood of various thickness vertically on the floor, then place your ear and the side of your head against them as you tap and scratch at each one to see what you think. A good size is 4 feet square, but this can be enlarged or reduced, again depending upon who is going to be using it. Too small a square and the resonant qualities will reduce dramatically; too large a square and the center of the board will sag and touch the floor when a person's weight is on it, seriously dampening the resonance. If the board is much bigger than 5 feet square then only tall, strong people will be able to lift and move it. I generally use 3-feet-square boards for babies and infants, and 4-feet-square boards for older children. As children with limited movement grow and get taller, I place them more diagonally on the board.

◆ *Four strips of 1-inch-x-1-inch wood* to be attached to the underside rim of the sheet of plywood (for example, on a 4-feet-square board each of these strips would need to be 3 feet 11 inches long). These can be glued around the underside rim, but if the board is likely to get a lot of use and a lot of lifting and moving around (in a school classroom rather than in a home), use glue plus nails or screws, tak-

ing care to countersink the nails or screws into the surface of the plywood for safety. Some people are concerned that using nails or screws deadens the resonant quality of the board, but I have found this to be so slight that it seems negligible.

◆ *One can of furniture wax and a polishing cloth.*

## How Do You Finish and Maintain the Board?

Once the board is constructed, the upper surface and edges need to be made very smooth and safe by rubbing with sandpaper and then glasspaper. The final step is to apply two coats of furniture wax with a polishing cloth (hard work!) so that the finished surface is smooth, rather waterproof, and easy to wipe clean. You might like the idea of using scented wax polish (such as lavender) to add a consistent smell as an extra marker to identify the board. When I made my first board in 1985, I painted it black for good visual contrast and for saliva proofing. It was a beautiful job with undercoat and two coats of black gloss paint, but I found that these layers of paint deadened the resonant qualities of the board very significantly. Painting the board with clear varnish does the same, so it is best to stick to wax polish.

Maintenance needs depend upon the amount and intensity of use that the board gets. The board I used for years got a lot of use and so needed to be rubbed down with glasspaper and rewaxed two or three times every year. If you see parts of the plywood surface losing their sheen or bits of frayed wood or splinters, you urgently need to make repairs, at least to rewax with the polishing cloth until you have time to glasspaper it smooth again. To save storage space, it is best to keep the board upright against a wall (maybe behind a cupboard or a sofa), with the smooth surface towards the wall for protection.

## What Can You Use on the Board?

Toys and equipment to be used on the board depend entirely upon availability, safety considerations, and personal preferences (yours and the child's!). I recommend access to a variety of things that includes plastic and enamel plates and bowls, metal chains of various lengths and weights (such as dog choker collars), bunches of metal spoons or keys, rocking toys with bells inside (such as Chime Bird and Happy Apple), plastic or metal Slinkies, spinning tops, metal cans of all sorts, music boxes, drumsticks, large round pebbles, and vibrating and wind-up objects. Since my arrival in California from England in 2000, colleagues at the Blind Babies Foundation have introduced me to the idea of using more natural materials like pieces of smooth driftwood and piles of walnuts and pecans (still in the shell, of course!). My favorite object to use on the board is myself. I like to knock and scratch on the board or talk and sing at it as a way of making contact with the child who is on it.

## How Do You Start Using the Board?

A child can be placed alone on the board or can use it with another child or with an adult in any safe, desired, or useful position. Standing and walking on the board barefoot can be fun, as well as sitting and lying down. Some children might enjoy being in their seat or standing frame on the board. For first-timers in the horizontal position the board can be a scary place in the beginning, so I often recommend spreading a towel over the board, so that it acts as a muffler to sounds and vibrations. The towel can be repositioned gradually as the child gets used to the sound and vibro-tactile qualities of the board, so that first bare feet touch the board, then the legs, then the butt, the torso and shoulders, and finally, if the child is happy and interested, you can remove the towel completely and expose the head to the bare wood. Some children may need days or weeks for this process, but others cope with it over the space of half an hour or so. Another idea is to begin with the child lying on the carpet with only his or her feet on the board. If sensitive feet are a problem you might want to reverse this position or just leave the child's shoes or socks on. You can place the board on carpet to minimize the resonance or move it to a hard floor surface like linoleum, tiles, or concrete to produce much more dramatic feedback. Sometimes a child on a chair, or in a wheelchair, or standing might like to interact with the board held vertically next to them (as you did in the timber shop when you first selected the wood).

## What Do You Do with the Board?

This is where all that hard work pays off and things get exciting! Use your imagination and the sky is the limit! You can work on an amazing range and variety of skills and activities using a board, including math, communication, large motor skills and mobility, fine motor manipulation, use of vision and hearing, tactile and visual search, turn-taking, anticipation, encouraging vocalizations and speech, problem-solving, sequencing, cause and effect, rhythm, and on and on. The special quality of the board is that any movement on its surface will produce amplified sound and matching vibration, and it will vibrate to music or voices aimed at it even if the sound-maker is not in direct contact with the wood. For children with deaf-blindness the amplified sound coming through the board might be important, but the vibration that accompanies the sounds will have an immense impact if the child is in direct contact with the board's surface, and this might be very motivating for them. Sometimes using a board can produce very interesting and surprising outcomes:

- A distractible and very active child who moves around the room a lot may choose to remain on the board because it is the place where all the interesting feedback happens, yet a very passive immobile child may become more active on the board because of the feedback it provides, and also because it has a smooth surface that reduces friction and makes sliding, bottom-shuffling, and back-scooting easier.

- A child with poorly coordinated movements might move less but move with more care and planning in order to produce specific feedback from the board, yet a passive and inactive child might be encouraged to move more because each arm or leg movement or turn of the head produces interesting feedback when he or she knocks the rocking toy, drags the metal chains draped across wrists or ankles, or just taps and kicks on the board directly.

- A very vocal child might be silent on the board in order to listen and attend, but a normally very silent child may vocalize in response to sounds and vibrations coming through the board.

- A child who does not normally use vision may look to see what is tapping or rocking on the board or may use vision to guide arm or leg movements to produce interesting feedback again.

- A child who dislikes using his or her hands to touch things might reach out to make sounds and vibrations happen again.

- Children who do not normally interact with other people in positive ways may attend, wait, look, touch, and take turns during tapping games on the board. Interactions with peers might be encouraged if children spend time together on the board. I have also observed in regular classrooms a board raised up onto a large table with the whole class sitting around it and playing games involving turn-taking, creating or accompanying music, or banging and chanting as part of a storytelling or drama session. Used in this way the board is an effective agent for including all the children in the class activity (Park, 2000).

- By traveling around the board in some way a child might discover the board's edges and use touch or vision to explore them, thus expanding their understanding of space and boundaries.

- A child with a poor sense of space and direction may be helped by tapping games on the board, since the vibrations through the wood will provide extra information about where the taps are coming from and where the other person is located.

- Sometimes a child might decide, or be encouraged to decide, to get himself on or off the board, and this can provide interesting challenges to problem-solving abilities.

As you can see from this list, many of the things that the board can encourage are often thought of as being in the areas of expertise of the physical therapist, the vision specialist, the orientation and mobility specialist, and the teacher of the deaf. If you have a board, any of these professionals can be brought in to explore it, to experiment with it, and to collaborate in developing ideas to help individual children. There are also other pieces of equipment designed or promoted by Lilli Nielsen (Nielsen, 1992; Johnson, Griffin-Shirley, & Koenig, 2000) that can be used with a resonance board. Above all, let the children you know show you how to use the board, and let your imaginations and creative impulses run free together. Discovering these boards almost twenty years ago changed my life in the most positive ways, and I hope the discovery changes your life too.

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### Seeking Parents to Review Assessment Tool

The Bringing it All Back Home Project is seeking parents of children who are deafblind to assist with the field testing of a recently revised assessment tool called *HomeTalk*. The project would like to learn about parents' experiences using this tool as part of an IEP review, triennial evaluation, or other educational planning meeting. If interested, contact Dr. Charity Rowland of the Oregon Institute on Disability and Development (rowlandc@ohsu.edu, 503-238-4030) or Dr. Harvey Mar of St. Luke's-Roosevelt Hospital Center (hhm1@columbia.edu, 212-523-6235).

# Capturing Change: Measuring the Impact of An Interagency Transition Team Approach

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*John is 19 years old and is deafblind. More than anything he wants a job and to earn money, but instead he sits at home each day. A year ago he graduated from high school with a regular diploma. The only assistance he received in planning for his transition to adulthood was when his school referred him to the state vocational rehabilitation agency in his final month of school. The vocational rehabilitation agency denied his application because of his vision loss and referred him to the state commission for the blind. The commission for the blind didn't feel that John could benefit from their vocational rehabilitation program because of his multiple disabilities and referred him to the state developmental disabilities agency. John's IQ scores were too high to qualify for the developmental disabilities agency services, however, and he was again denied services that would help him attain his employment goal.*

*In the meantime, a year has passed. John's mother, a single parent, left her job to stay home and care for John's physical and medical needs. The little respite she gets is through a program that will end when John turns 21 years old. She is broke, tired, and frustrated, but continues to try to find resources that will help John find a job. Had comprehensive transition planning occurred while John was in high school, things might have turned out differently.*

While John's story is tragic, it is typical of what happens to many students who are deafblind. Research indicates that achieving successful transitions from school to adult life remains problematic at best and woefully discouraging at worst (Petroff, 2001; Blackorby & Wagner, 1996; Lawson & Everson, 1994; Wagner, 1992). Successful transition for those who are deafblind is especially difficult because of the diverse needs of this low-incidence population in areas such as communication, mobility, meaningful vocational opportunities, living arrangements, and access to social interactions.

How can John and others like him be helped? The work of a number of researchers (Petroff, 2001; Everson & Guillory, 2002; Flannery et al., 2000; Goetz, Jacob, & O'Farrell, 2001) has identified two important strategies to help students plan for their future: person-centered planning and the use of a team-oriented approach in which individuals from different agencies work together with the student and family. This article describes a transition team model and training program that uses both of these strategies and a new tool that can be used to measure the effectiveness of this approach. The model is based on the work of a federally funded project, the Helen Keller National Center–Technical Assistance Center (HKNC–TAC). From 1991 through 1996 HKNC–TAC used an approach to transition planning that emphasized interagency collaboration to achieve quality outcomes for individuals who are deaf-blind (Rachal, 1996). The success of the approach inspired us to refine the HKNC–TAC model and to develop ways to measure its effectiveness in bringing about change.

## Interagency Transition Teams

The person-centered interagency team approach is straightforward and simple: (a) identify key players in a state or locality who are willing to create teams centered around specific transition-age students who are deaf-blind, and (b) use the team members' combined expertise and knowledge to address obstacles to successful transition. The approach requires the involvement and oversight of leaders based in agencies, organizations, or grant-funded projects to create and train teams, to track and assess outcomes, and to identify successful strategies that can be shared with others. The lead agencies recruit members for each team and host a series of three workshops over the course of a year or a year and a half. The resources used to conduct the training have come from a variety of sources including state deaf-blind projects, departments of education, vocational rehabilitation agencies, commissions for the blind, state developmental disabilities agencies, state transition and employment initiatives, the Helen Keller National Center, and the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC).

The teams consist of students, family members, school personnel, and adult service providers who work together to positively impact the student's future. There are always two goals for each team: (a) to enable the focus student to reach his or her desired goals, and (b) to identify barriers within the state or local system that need to be addressed so that other students will also benefit from the team's efforts. Teams meet on a regular basis approximately once a month

between the three training sessions to evaluate how well the plan for the student is working and to make adjustments as needed.

The whole team receives training together. This has an advantage over training activities that are delivered based on a professional role or position (e.g., teachers attending training with other teachers, vocational rehabilitation counselors with other counselors, and family members with other families). While separate trainings have their place, transition planning requires that people with various roles work together and learn from each other. Bringing the whole team together for training gives members an opportunity to apply what they have learned to an individual student's situation, to understand the requirements and procedures of involved agencies, and to reduce the need for one team member to train the others.

Multiple teams may be trained simultaneously, usually 4 to 5 at a time, but the approach has worked successfully with as many as 9 teams at one time. Participating in a training program together allows teams to share their concerns, successful strategies, and resources.

## Transition Team Training

The training program involves the following:

### Instruction about person-centered planning

Teams learn how to develop a person-centered plan, which is used to identify the focus student's adult goals and plan educational activities and the interagency linkages and responsibilities needed to reach those goals. Person-centered planning is "a creative process designed to help a group of people craft a life of meaning and contribution for the person who is the focus of the planning" (Mount & Zwernik, 1994). Teams are frequently asked to refer to the information captured in the person-centered plan (e.g., How could Jane's interests and preferences be matched to a job or work experience? What choices are made for Tara that she could make herself?).

### Instruction about transition issues for young adults who are deafblind

Topics covered include addressing transition needs in the individualized education program (IEP), creating job opportunities, promoting self-determination skills, acquiring assistive technology, developing community living options, accessing recreational and leisure supports, connecting with mentors, navigating the Social Security system, utilizing work-incentive programs, and understanding eligibility requirements and services provided by adult service agencies.

### Team-building activities

While teams need to learn specific concepts about transition such as job development and independent living, they also need to learn to work together as a team. Team evolution doesn't happen overnight. It evolves over time as team members learn each other's strengths and abilities, how to communicate effectively, and how to work together productively. During the training, teams are given tools to encourage cooperation. These include such techniques as interactive communication and feedback skills, meeting effectiveness strategies, problem-solving methods, team value-identification exercises, team self-assessment strategies, and action planning processes for enhancing individual and team accountability.

### Learning to evaluate change

During the course of the three trainings, teams are frequently asked to reflect on their progress. Regularly reflecting on team goals and working methods as well as on successes and challenges can produce valuable information about changes that have occurred. More concrete tools have also been developed, such as Change Indicators for Transition Teams (discussed below) and tools to measure improvements in individualized education programs (Steveley, 1999; Storms, O'Leary, & Williams, 2000).

## Measuring Impact

### Change indicators

To determine the effectiveness of the interagency approach and training program, we developed an evaluation tool called *Change Indicators for Transition Teams* (Goehl, Rachal, & Steveley, 2002). The indicators were field-tested in three states (South Carolina, Indiana, and Kansas) by collecting data from local team members actively involved in using the model described above. The tool was designed to document change in five areas: (a) student outcomes, (b) family outcomes, (c) collaborative planning/team outcomes, (d) IEP document and process outcomes, and (e) local system outcomes (see table for sample indicators). Team members were asked to evaluate changes that had occurred as a direct result of participating in the interagency transition team training by rating each indicator using a 4-point scale:

1.  Definite change has occurred;

2.  Some change has occurred;

3.  No change has occurred; or

4.  A decrease has occurred (a change for the worse).

The surveys were distributed to 45 team members as part of the field test. Of the 32 surveys returned, respondents reported many positive changes as a result of the training and work of the transition teams.

Student changes

- Increased participation in the community (75%)
- Increased participation in job training opportunities (75%)
- Increased interaction with peers and community members (87%)
- Development of self-determination skills (69%)

Individualized education program (IEP) and educational program planning changes

- IEPs reflected student interests and preferences (75%)
- Increased parent and family involvement (72%)
- Increased adult service agency involvement in the IEP (72%)
- Improved identification of interagency linkages and responsibilities in IEPs (62%)
- Clearer relationship between projected adult outcomes and IEP goals (90%)

Team/system changes

- Developed a clearer vision of the future for the focus student (81%)
- Used the information and strategies learned with other students or clients in their communities (69%)
- Increased sharing of funding responsibilities among agencies or identification of alternate funding sources to support student needs (78%)

All of the participants surveyed felt the training would not have been as effective if team members had received the same training separately.

### Individual student change

Often change is best captured by the successful stories of individual students. Emily T.'s team applied to participate in interagency transition team training when Emily was 16 years old. At that time, Emily had just started high school. One area of concern for Emily's team was how to prepare Emily for future job opportunities. Because the team members knew she would potentially be difficult to place in a job because of her multiple sensory, cognitive, and physical disabilities, they considered self-employment as a potential option. The team wanted to create a job experience for her in which she could have some personal control and which would give her an overview of entrepreneurship. The team envisioned a project that would allow her to learn new concepts (such as taking inventory) while working on basic job skills and having the experience of working away from school.

In order for the job experience to be a success, Emily's team members knew they would need to focus on something that would hold her interest and that she would be happy doing. Using the per-

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### SAMPLE INDICATORS

#### Student Outcomes
- The student is provided with job training opportunities (e.g., community-based work experience, participation in school-to-work programs, summer employment).
- The student has access to needed technology.
- The student is developing daily living skills.

#### Family Outcomes
- The student/family has accessed the adult service system (e.g., understands eligibility requirements, has made application, or currently receives services from an adult agency).
- The student/family can identify funding sources available to support student goals (e.g., Social Security Work Incentives, Work Opportunity Tax Credit).
- The student/family feels supported by and trusts team members.

#### Collaborative Planning/Team Outcomes
- The team has a clear vision of the future for this student.
- Agencies are blending funding or identifying alternate funding sources to support student outcomes (e.g., vocational rehabilitation agency helping with summer work experiences, use of Social Security Work Incentives).
- Adult service representatives are involved in IEP and program planning.

#### IEP Document & Process Outcomes
- IEP forms and/or planning process meets IDEA requirements.
- Student goals are related to identified outcomes.
- Student preferences and interests are addressed in the IEP.

#### Local System Outcomes
- Information and strategies have been applied to other students/clients in the community (e.g., person-centered planning, meeting effectiveness, funding for employment supports).
- Local policy or procedures have changed to support better transition outcomes for youth with disabilities.

son-centered planning techniques they had learned, they identified one of her greatest interests as "messing with paper." Emily loved to hold paper, to feel it, to crumple it, and to draw on it. Creativity and persistence on the part of the team has allowed Emily to test out a self-employment opportunity that involves producing and selling packaged gift bags and accessories. She purchases empty brown paper bags with handles and uses a variety of stamps to create patterns on the bags for different holidays and occasions (such as snowflakes for winter holiday bags). Matching gift cards are also cut and stamped. Emily then shreds paper to package with the bags and cards as packing material. The items are placed into a clear plastic bag and sealed with a sticker. Perhaps the most creative part of this business is its name, The Em. T. Bag Company, taken from Emily T.'s name!

While the Em. T. Bag Company may not be a long-term job, it has given Emily valuable work experience and opportunities to connect with others. For example, her circle of friends, a group of approximately 12 to 14 peers who meet twice a month to help Emily plan and solve problems, helped Emily with a Christmas card project and expanded her social network. In addition, the job has taught her skills useful in her current work experience at a medical center labeling inventory items.

### State and local state systems change

Using a person-centered team approach has consequences that go beyond specific enhanced student outcomes. Changes in systems can also be achieved. These include new or altered processes or procedures that impact many other individuals who are deafblind or have other disabilities. One such change occurred at the Indiana State School for the Deaf (ISD). During school year 2000–2001, two teams from the school participated in transition team training sponsored by the Indiana Deafblind Services Project. Because the Indiana School for the Deaf is a residential school that serves students from across the state, meaningful transition planning requires much more than discussions of needed transition services during a student's annual IEP meeting. A more intensive and ongoing approach is required. The ISD administration decided to initiate person-centered, action-oriented transition teams with the long-range goal that every sophomore student would be part of a team focusing on the transition from school to adult life. A staff person is in charge of transition team development, and currently a transition-planning group meets weekly. The group began by prioritizing those students needing transition teams immediately. It is also developing a transition team process for the school with initial implementation planned for the 2002–2003 school year. The team has developed a

PowerPoint presentation on person-centered planning for all eighth grade students and their parents.



Emily T.

## Summary

Successful transition from school to adult life requires input from individuals with a variety of backgrounds and expertise, and it is crucial for families, schools, and other involved agencies to work together. The approach described here involves creating teams and asking team members to commit to a process with a person-centered focus to achieve tangible, concrete outcomes. Capturing data and measuring change are essential for identifying and implementing strategies that hold the highest promise of positive transition outcomes. The results of our survey indicate the effectiveness of this one approach.

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# Book Review

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*Understanding Deafblindness: Issues, Perspectives, and Strategies.* Alsop, L. (Ed.) Logan, UT: HOPE, Inc., 2002. $160.00.

*Understanding Deafblindness: Issues, Perspectives, and Strategies* comprehensively presents key concepts and strategies useful to parents, teachers, paraeducators, and others who want to understand and respond to the unique needs of children who are deafblind. This thoughtful effort is presented in two volumes, organized by the following chapters: Introduction, Psychosocial Aspects, Concept Development, Intervention, Vision, Hearing, Touch, Sensory Integration, Neurological Issues, Health, Communication Basics, Early Communication, Communication Interactive Relationships, Calendar Systems, van Dijk Perspectives, Family Issues, Self-Determination, Behavior, Gross Motor, Fine Motor & Play, O&M Children, O&M Adolescents, Daily Care & Self Help, IFSP/IEP, Physical Activity, Social/Sex Education, Transition, and Community Support. The chapters are organized within two loose-leaf notebooks.

*Understanding Deafblindness* covers a wide range of topics. Here are examples from each of the chapters:

- the isolation of deafblindness
- differentiating skills from concepts
- the roles of the intervener
- questions to ask an eye doctor
- troubleshooting hearing aid problems
- establishing mutual tactile attention
- the role of massage in bonding
- hand under hand technique
- alertness states
- stress in babies
- communication cues
- transdisciplinary teaming
- the importance of touch and touch cues
- calendars as "time pieces"
- the child who functions at the thalamus level
- advice to parents to be "respectfully demanding" of professionals
- self-determination as a lifelong process
- being preventive not reactive to difficult behaviors

- the basic principles and sequence of gross and fine motor development
- use of the Little Room to achieve motor and cognitive goals
- the role of each sense in orientation and mobility
- the range of orientation and mobility skills
- introducing new foods
- differentiating the Individualized Family Service Plan (IFSP) and the Individualized Education Program (IEP)
- the importance of naming physical activities
- social/sexual education as proactive and concrete
- a shared vision for transition
- identification of supports in the community

Clearly, this is a work with appeal for a broad audience.

*Understanding Deafblindness* is extremely readable, and that readability is sustained across all chapters. This is quite a feat considering that the volumes, edited by Linda Alsop, had more than 35 contributors. Challenging topics such as the structures of the ear, eye, and brain are made accessible to the reader, making this a useful supportive text for teacher preparation programs.

The authors have utilized many effective design strategies to highlight important points. The carefully planned use of font sizes, bold type, italics, bullets, and boxes set off key ideas for emphasis. Key concepts are also highlighted through the use of unique "points to remember" sections. Topics are enhanced through the use of case stories, and there is a reference list at the end of each chapter that identifies additional sources of information.

The table of contents outlines the range of topics addressed within each of the chapters. This is helpful because the text includes many hidden treasures that one would not expect based on the chapter titles alone. A strength of *Understanding Deafblindness* is that key concepts such as the importance of using a hand under hand technique are addressed in more than one chapter, with authors cross-referencing each other's work. This makes it possible to experience various perspectives on a similar topic, while reinforcing the importance of key concepts and skills.

The greatest strength of this text lies in how the ideas are expressed. The authors' sensitivity and respect for individual learners is evident. The child who is deafblind is at risk for experiencing a severely re-stricted world, and it is through sensitivity and respect that we are allowed to experience the child's ways of knowing, while gently expanding the child's experience of the world.

Publisher's contact information: HOPE, Inc., 1856 North 1200 East, North Logan, UT 84321. Phone/Fax: 435-245-2888. E-mail: hope@hopepubl.com. Web: http://www.hopepubl.com.

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*NTAC*

# Report on the 2002 Annual Project Directors' Meeting: Projects for Children and Young Adults Who Are Deaf-Blind

Peggy Malloy

Each fall, NTAC (The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind) assists the U.S. Department of Education's Office of Special Education Programs (OSEP) to hold a national meeting for people who work on federally funded projects for children and young adults who are deaf-blind. Staff from the state deaf-blind projects, DB-LINK, NTAC, and model demonstration projects attend the meeting. All of these programs are funded by OSEP. The meeting, commonly called the Project Directors' Meeting or PDM, provides both professional education activities to support the work of the projects and an opportunity to hear from Department of Education officials about new federal initiatives. Working with Charlie Freeman, project officer for OSEP's deaf-blind projects and a planning committee, NTAC staff members work throughout the year to make the meeting a truly useful and educational event. The most recent meeting was held in Arlington, Virginia, in October 2002.

The two-and-a-half-day event included a wonderful keynote address by Barbara Miles followed by sessions on a wide variety of topics. Barbara Miles spoke about the essential qualities of conversation and how

an understanding of these qualities can guide conversations with children who are deaf-blind (see the short summary following this article).

## Department of Education Representatives

Representatives from the U.S. Department of Education spoke on a variety of topics including the No Child Left Behind Act, the recent report by the President's Commission on Excellence in Special Education, the upcoming reauthorization of the Individuals with Disabilities Education Act (IDEA), and current activities in the Research to Practice Division of OSEP. The Research to Practice Division oversees OSEP technical assistance and dissemination projects, which include all of the deaf-blind projects. The speakers were:

- Robert Pasternack, Assistant Secretary for Special Education and Rehabilitative Services
- Patty Guard, Deputy Director, OSEP
- Lou Danielson, Division Director, Research to Practice Division
- Ingrid Oxaal, Assistant Division Director
- Charles Freeman, Project Officer, Deaf-Blind Projects, Research to Practice Division

## Topical Sessions

Topical sessions were presented by individuals who work on model demonstration projects and by other professionals in the field of deaf-blindness.

### Model Demonstration Projects

Model demonstration projects are OSEP-funded projects devoted to a specific topic or initiative. Their purpose is to develop, improve, or demonstrate new or existing methods, approaches, or techniques for serving students with deaf-blindness. Four recent projects gave presentations:

- *Project SALUTE: Successful Adaptations for Learning to Use Touch Effectively* (http://www.projectsalute.net). Deborah Chen gave an update of the project and discussed tactile strategies for children who are deaf-blind.

- *Project SPARKLE: Supporting Parent Access to Resources, Knowledge, Linkages, and Education* (http://www.sparkle.usu.edu/). Linda Alsop, Sally Prouty, and Ralph Warner gave an overview of the SPARKLE model of individualized learning for families of children who are deaf-blind.

- *Bringing It All Back Home: Family-Driven Assessment and Intervention for Children Who Are Deaf-Blind*. Harvey Mar, Charity Rowland, and Philip Schweigert presented a new assessment instrument called *Home Talk* that is currently in development.

- *Learning to Learn: A Systematic Child-Centered Model for Skill Development in Young Children Who Are Deaf-Blind*. Charity Rowland and Philip Schweigert described assessment instruments designed to measure both child skills and environmental support for child skill development.

### Other Topical Sessions

Jay and Marilyn Gense spoke about identification of autism spectrum disorders in children who are deaf-blind. Sarah Beaird and John Killoran addressed issues related to the national census of children who are deaf-blind. In a presentation called "My life is more than 9–5: Looking at Life Outside of Work," Michael McCarthy spoke about strategies to assist people who are deaf-blind or have other disabilities to explore options for a meaningful and enjoyable life outside of work. Jennifer Grisham-Brown, Brent Garrett, and Tanni Anthony discussed the work of a current research project about including students with deaf-blindness in large-scale assessments (http://www.ihdi.uky.edu/kydb-research).

There were three panel discussions with professionals from a number of state deaf-blind projects, who shared their experiences on the topics of distance technology, effective training programs, and transitions across the lifespan. Presentations updating participants about current activities in their respective agencies were given by NTAC staff members; Sheri Stanger, the new president of NFADB (National Family Association for Deafblind); and DB-LINK. DB-LINK celebrated its tenth birthday this year with a big cake.

One of the best things about the annual Project Directors' Meeting is the opportunity it provides for participants to share information and learn from one another. As in previous years, participants at this year's meeting socialized and networked at both organized events and informally. The meeting is a unique event that allows participants to obtain essential information about new issues in the field.

Editor's Note: For more information about any of the topics mentioned in this report, contact:
DB-LINK (800-438-9376, 800-854-7013 TTY, dblink@tr.wou.edu).

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## Conversations: Seeds for a Diverse, Flowering Future

What makes a good conversation? This was the question addressed by Barbara Miles, keynote speaker at the 2002 Project Directors' Meeting. Barbara, a national consultant for deaf-blindness and co-author (with Marianne Riggio) of the book *Remarkable Conversations: A Guide to Developing Meaningful Communication with Children and Young Adults Who Are Deafblind*, said that to understand the essence of conversation, think about a really great conversation that you have had and ask yourself, "What are the basic elements of a good conversation?" She said that when she asks this question of people with whom she works she almost always gets responses that include the following:

- Mutual respect
- Physical comfort that allows undivided attention to each other
- A common topic or topics of mutual interest
- Balanced turn-taking
- Comfortable pacing
- The feeling on everyone's part of being heard and understood
- New learning

These elements form the basis for all good conversations including those with children who are deaf-blind, regardless of the form of communication used. For more information about this topic, contact DB-LINK (800-438-9376; 800-854-7013 TTY; dblink@tr.wou.edu).

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## Western Region Usher Family Weekend

Marcia Fankhauser and Nancy Hatfield
Washington State Services for Children with Deaf-Blindness

On a golden Friday afternoon last September, a number of families of children who have Usher Syndrome, deaf-blind adults, interpreters, volunteers, and staff from three state deaf-blind projects flew or drove, braving Seattle's infamous rush-hour traffic, to reach Camp Berachah, nestled in the Cascade Mountains with Mount Rainier forming the backdrop. What was the occasion?

Four years ago the state deaf-blind projects of Arizona, Oregon, and Washington realized they had a joint need and wish to host a weekend retreat for families of children who have Usher Syndrome. Each state included specific funding in their proposals submitted to the U.S. Department of Education Office of Special Education Programs in 1998 to support this venture.

The three state deaf-blind projects, the California deaf-blind project, and NTAC Region 1 staff collaborated for more than a year. The planning resulted in the retreat held September 20–22, 2002, at Camp Berachah, 30 miles southeast of Seattle. Washington was chosen as the host site because of its large adult community of individuals with Usher Syndrome who could participate in the weekend, as well as its pool of interpreters skilled in working with individuals who are deaf-blind.

Eleven families from Arizona, Oregon, Washington—and Missouri!—participated in the weekend, including 12 students with Usher Syndrome or retinitis pigmentosa plus a hearing loss. A survey of the families indicated a broad range of topical interests. Their primary interests seemed to be in the areas of adult life, career choices, and training.

With information from families about the students who would be attending, Jelica Nuccio, a Seattle resident who has Usher Syndrome, worked with the committee to identify adults who are deaf-blind who were representative of the backgrounds and communication modes of the students. Barry Jensen, Lorie Cook Noel, Liz Stone, and Bruce Visser, deaf-blind adults from the Puget Sound region, shared their lives, with great warmth and humor, with the parents, students, and project staff.

A variety of learning options were provided for parents and older students, in addition to fun activities offered for younger children. These options included a presentation on recent research about Usher Syndrome by Jelica Nuccio (who also facilitated the panel of adults with deaf-blindness); a demonstration and discussion of assistive devices by Ed Gervasoni from the Arizona State Schools for the Deaf and the Blind, who also worked with the older youth on orientation and mobility issues; a parent support group facilitated by Marlyn Minkin, a counselor from the Seattle area; and several discussions with our adult panelists.

The weekend was a useful venue for sharing information and resources and for developing new friendships. Families, project staff, and consultants learned from each other, from the adults with Usher Syndrome, and from the interpreters through structured activities, and perhaps even more, during unstructured moments. Many "ah has" happened spontaneously in this setting. During the minutes prior to sessions when interpreters were getting positioned

and lighting and background were being adjusted, families learned about environmental conditions that could be changed in their homes. Many did not know that deaf individuals often interpret for deaf-blind individuals. Nor did they realize that tactile sign can allow people with deaf-blindness to scan the room during activities, much in the way that hearing people listen and look around at what else is happening in the environment. We all learned how important tending to details of timing and process are to insure that communication happens in a group with such diverse needs.

All of the adults delighted in watching interactions among the youngsters and young adults, who ranged in age from 4 years old to 21. Some were fluent in ASL, several used speech and audition, some used canes, and a few were skilled in Braille. Skillful interpreters facilitated communication as the students got to know each other. The youngest children zoomed around on trikes or swam in the indoor pool; the teenagers giggled together as they sat at round tables, making bead bracelets and masks; the oldest "kids" played cards.

Meals were shared, family style, in the camp lodge; lattes were available during the morning hours. On Saturday evening after a series of hilarious performances by Deaf storyteller Terry Dockter, Barry Jensen, and the deaf-blind panel participants, many "campers" stayed up until after midnight. They walked in the fields in the light of the full moon, rode a tandem bicycle, played cards, and just chatted. Without exception, children and adults alike felt that the weekend was too short!

The comments we received from participants indicated that the weekend was a big success.

### Comments from parents:

*We have received different ideas on how to work with our daughter concerning her vision and hearing.*

*It was great to learn about interpreters and other assistance services; we didn't know so much was available.*

*This was our first experience meeting adults with Usher. Very reassuring; I was thinking my son would never have a job or career. The adult panel was the best part of the weekend.*

### Comments from teens:

*Being a young adult with Usher, this weekend provided me with my first encounter with others with Usher. I've gained a clearer picture of my future.*

*Having met the individuals on the panel, I no longer envision myself as one of those little old blind ladies that everybody rushes by on the street.*

*I have enjoyed meeting people my age who have Usher.*

*It's wonderful to meet adults with Usher living interesting and fulfilling lives. We know we are not alone.*

*I learned how to rely on interpreters because I don't have signing skills.*

*I am just learning to use a cane; even though I can see I am probably missing things. I am more aware of how other people with Usher get over being "noticed" by the adaptive equipment I need.*

*This was a new experience to me, opened my eyes about things I can do in my life, about Usher Syndrome, things I didn't know about.*

### Comments from staff and planning committee members:

*Deaf-blind adults need to be part of the whole weekend—from planning through the last goodbye.*

*Having an adult with deaf-blindness facilitate the discussions was positive.*

*The deaf-blind adults come up with topics/issues and ways to approach them with the students that parents and staff don't necessarily think about.*

*Interacting directly with the adults who use the techniques dispels the scariness of some issues, like tactile signing for some.*

*Unstructured time is as valuable as structured.*

*It's good to involve deaf-blind adults who match the students' communication styles.*

*The networking during activity times (e.g., games and crafts) was a real plus. Be flexible with the kids' programming to give social time when necessary; and take advantage of learning opportunities that arise.*

*We need to hold the weekend more often. There is never enough time during one weekend.*

The benefits of "hands on" interactive weekends are worth every bit of planning and collaboration for the learning, structured and unstructured, that occurs for everyone involved. In the course of simply "being" with each other, we gain the experience and confidence to learn.

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# For Your Library

### Communication Fact Sheets for Parents

*McNulty, K. (Ed.). Monmouth, OR: NTAC, The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, 2002.*

This booklet contains fact sheets covering a wide variety of topics including communication development, the forms and functions of communication, and different methods, of communication. It is available on the NTAC Web site http://www.tr.wou.edu/ntac/publications.htm or by contacting DB-LINK. Phone: 800-438-9376, TTY: 800-854-7013. E-mail: dblink@tr.wou.edu.

### Move and Discover: The Active Learning Approach for Children with Disabilities (Videotape)

*North Dakota Deafblind Services Project and University of North Dakota TV Center, 2002.*

This video is based on Lilli Nielsen's active learning philosophy for children who are blind. Through movement children can discover texture, shape, weight, quantity, temperature, and spatial relationship. The North Dakota Deafblind Services Project collaborated with ND Vision Services/School for the Blind and the University of North Dakota in this professional production. For more information contact Colleen Sanford, Project Coordinator, ND Deafblind Services Project, 500 Stanford Road, Grand Forks, ND 58203, Phone: 701-795-2741. E-mail: Colleen.Sanford@sendit.nodak.edu.

### Interagency Teaming: Strategies for Facilitating Teams from Forming Through Performing

*Everson, J. M. & Guillory, J. D. New Orleans: Human Development Center, Louisiana's University Center for Excellence in Developmental Disabilities Education, Research, and Service, Louisiana State University Health Sciences Center, 2002.*

This practical manual describes a model of team development and functioning and provides a step-by-step process that can be used for interagency team initiation and development. To order contact Ann Dimes, Human Development Center, LSUHSC, 1100 Florida Avenue, #119, New Orleans, LA 70119. Phone: 504-942-8230. TTY: 504-942-5900. FAX: 504-942-5908. E-mail: adimes@lsuhsc.edu. Cost: $12.50 including shipping and handling. Send check or money order payable to LSUHSC with the notation "Teaming Manual" in the memo section.

### Assessing AT Student Need

*Zabala, J. & Reed, P. Assistive Technology Online Project, University of Buffalo, 2000-2002.*

This is a Web-based manual that addresses the following topics: consideration of assistive technology (AT) for students with disabilities, components of AT assessment, the assessment process, and integration of AT devices and services into the IEP. It is written in straightforward language and uses a step-by-step approach. Web: http://atto.buffalo.edu/registered/ATBasics/Foundation/Assessment (*there are no hyphens in the address*). The Web site where this manual is located also has additional useful information about assistive technology (http://atto.buffalo.edu).

### Assistive Technology Consideration Quick Wheel (AT Quick Wheel)

*The IDEA Local Implementation by Local Administrators (ILIAD) Partnership, The Technology and Media (TAM) Division of the Council for Exceptional Children (CEC), & The Wisconsin Assistive Technology Initiative, 2002.*

Another assistive technology tool, this quick wheel can be used to access a generic list of AT tools for a variety of tasks. One side of the wheel lists federal definitions of AT devices and services. The other side provides information about resources including books, journals, newsletters and Internet sites. Both sides include a generic list of AT tools to consider in a number of topical areas. Available from the Council for Exceptional Children (CEC). Phone: 888-232-7733. TTY: 866-915-5000. E-mail: service@cec.sped.org. Request product number P5550 for a single order or P5551 for a bulk order. Cost: $7.95 for a single copy and $2.50 each for 50 or more.

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# Conferences and Events

### Special Topics Workshop on Calendar Systems
### February 20–22, 2003
### Baltimore, MD

Robbie Blaha from the Texas School for the Blind and Visually Impaired will present this workshop on calendar systems.

*Contact:*
Diane Kelly
Connections Beyond Sight and Sound
University of Maryland
Department of Special Education
1308 Benjamin Building
College Park, MD 20742
301-405-7915 (Voice/TTY)
Dmkannap@aol.com

Cortical Visual Impairment Workshop
April 1–3, 2003
Aberdeen, South Dakota

This workshop cosponsored by the North Dakota Deafblind Project and the South Dakota Deafblind Project will be presented by Christine Roman.

*Contact:*
Colleen Sanford
701-795-2741
Colleen.Sanford@sendit.nodak.edu

Susan Parr
605-357-1437
Susan.Parr@usdmed.org

American Association of the Deaf-Blind (AADB)
Conference
July 12–18, 2003
San Diego, California

AADB is a national consumer advocacy organization that promotes better opportunities and services for deaf-blind people. The 2003 conference will be held at San Diego State University.

*Contact:*
AADB
814 Thayer Ave, Suite 302
Silver Spring, MD 20910-4500
301-495-4403, TTY: 301-495-4402
tomjill@juno.com or mcnamara@aadb.org
http://www.tr.wou.edu/dblink/aadb.htm

Deafblind International Conference 2003
Mississauga, Ontario, Canada
August 5-10, 2003

*Contact:*
Stan Munroe
519-372-2068, Fax: 519-372-0312
stan.munroe@sympatico.ca
http://www.dbiconferencecanada.com

# Announcements

## $2.5 Million Grant to Study Persons Aging with Hearing and Vision Loss

A five-year federal grant of $2.5 million from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR) is expanding the work of the Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision at Mississippi State University (MSU). The project will explore ways to improve employment and community integration outcomes for persons who are blind or deaf and who are experiencing a secondary onset of hearing or vision loss resulting from aging. The project is a collaborative effort of the MSU-RRTC, the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands Point, NY, and the RRTC on Persons who are Hard of Hearing or Late Deafened at National University in San Diego, CA. The RRTC on Blindness and Low Vision was established in 1981 and remains the

only one of its kind funded by NIDRR. For more information, contact Mrs. B.J. LeJeune, Project Director. Phone: 662-325-2001. TTY: 662-325-8693. E-mail: BJLeJeune@colled.msstate.edu.

## Alabama Quarter to depict Helen Keller

Alabama's state quarter, which will begin circulating in March, will feature Helen Keller. The design includes an image of Keller reading a book in Braille. Her name will appear on the coin in both English and in Braille, which has not previously been used on a U.S. coin in everyday use. The slogan "Spirit of Courage," is intended to draw attention to education. The Keller coin will be the 22nd quarter issued in the U.S. Mint's state quarters program, a 10-year project to salute all 50 states. Alabama was the 22nd state admitted to the Union.



## Position Announcement (Boston College)

The program in Severe Disabilities and Deafblindness at Boston College has an opening for a full-time, non-tenure track faculty member to serve as Grant Coordinator. Responsibilities include teaching, advising, and maintaining data on grant activities. A more extensive description is posted in the jobs section of the DB-LINK Web site (http://www.tr.wou.edu/dblink). For more information contact Dr. Susan Bruce, 120 Campion Hall, Boston College, Chestnut Hill, MA 02467-3813. Phone: 617-522-4239. Fax: 617-522-4239. E-mail: susan.bruce@bc.edu

## A Worldwide Network for Parents of Deafblind Children

A new international network of parents of deafblind children is being developed by the parents of the European Deafblind Network (EDbN). The goal of the parent network will be to support parents in their work with people who are deaf-blind, with professionals, and with volunteers; to facilitate the exchange of ideas and experiences; to create projects of common interest; and to develop new knowledge through international cooperation. The official languages will be English and Spanish. Communication will occur through a specific e-mail list, a Web site, and a newsletter. The developers hope to present the network at the 13th Deafblind International Conference in Canada in August of 2003. For more information or to register contact Ricard López, Cr Almeria, 31 Atic, 08014 Barcelona, Catalan Countries, Spain. Phone: + 34 93 305 43 85. E-mail: talking3@teleline.es.

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