Imagine that you are about to be interviewed for an important job. You prepare by anticipating questions, considering what the employer is looking for, and thinking about what makes you uniquely suited for the position. You arrive at the interview nattily dressed and confident. There’s some idle chat, and then the interview begins in earnest. You are asked, “How many days make a year on the planet Neptune? Name the currency of Myanmar. In what direction is the Leaning Tower of Pisa leaning?” When you look puzzled, the interviewer clucks and shakes her head, jots down a few notes, then continues with other questions that really have nothing at all to do with the job. You leave the interview feeling like “the weakest link,” knowing that you did not have a chance to demonstrate your competence.

As ludicrous as it sounds, this experience may not be so different from what students who are deafblind go through in traditional psychological evaluations. Such evaluations involve the use of formal tests to obtain information about a person’s intelligence, language skills, academic abilities, social competence, and emotional functioning. There are literally thousands of psychological tests. But unfortunately, most tests are not appropriate for use with individuals who have dual sensory impairments and other disabilities because they require normal vision and hearing and because they were developed for use with children in general education programs.

Yet, in schools across the country, the “competencies” of deafblind children and adolescents are often judged by tasks that are invalid because they have little connection to the students’ actual learning experiences, achievements, or educational needs and goals. When these tests are administered to deafblind students, whose curricula have been individualized throughout their school years, the students typically perform poorly. The “results” may reflect low IQ or achievement scores. They may focus on one’s delays and disabilities instead of true capabilities, leaving students and their families disheartened. Indeed, in one recent survey of parents and guardians of school-age children who are deafblind (Mar, 1998-1999), 43 percent of the respondents felt that the findings of recent psychological evaluations were not useful or did not accurately reflect the skills of their children.

Suppose that the job you are applying for is that of a store manager or an information technician or a home health aide, and suppose that the questions now have to do with work experience. No matter that you’re the
perennial loser of Trivial Pursuit, the interviewer seeks to assess your competencies in the context of the work environment. What special skills and knowledge will you bring to the job? How will you identify and address problems? Will you be able to interact and communicate well with others? In this interview, there is close correspondence between the skills being assessed and the skills required for the job.

Similarly, an assessment that seeks to understand how a deafblind student actually performs functions, understands tasks, and responds socially is usually more meaningful to students, teachers, and their parents. Areas of evaluation, like communication and life skills, are relevant to the student's educational goals. "Results" of the evaluation are viewed in terms of the student's progress toward those goals and the degree of participation in tasks and routines, as opposed to failures or lack of knowledge. Instead of the use of formal intelligence tests, this type of evaluation may involve observations of the student in everyday school and classroom environments and routines; interviews of teachers, parents, and peers; or interactions between the evaluator and the student during typical learning activities.

So why don't psychologists and other evaluators simply change their ways? There are several reasons. Many psychologists lack familiarity with the unique educational issues and challenges of students who are deafblind and resort to "standard" assessment procedures. Graduate schools and training programs may not teach alternative procedures for evaluating children with "low incidence" disabilities. School districts may insist on getting IQ scores or other quantitative data to qualify students for special educational services.

Several states and agencies have been acting to address these problems. One innovative program was designed by the Indiana Deafblind Services Project, which aimed to provide training and technical assistance to school psychologists, educators, families, university faculty, and other service providers. The program was called PHASES, an acronym for "Psychologists Helping to Assess Students' Educational Strengths." PHASES was designed as a systems change program that focuses on providing inservice training to psychologists across the state of Indiana. PHASES involved collaboration among the Indiana Deafblind Services Project, the Division of Special Education of the Indiana Department of Education, and the Indiana Association of School Psychologists.

### The PHASES Project

PHASES grew out of a clear need that was voiced, in part, by school psychologists responsible for the assessment of students with deafblindness. In 1997, the Indiana Deafblind Services Project sponsored a statewide needs assessment of school psychologists' practices, competencies, and training needs (Newman, 1997). A questionnaire was distributed to 373 school psychologists, of whom 158 responded. Some 87 percent of the respondents indicated interest in participating in a training program; 60 percent had not attended any inservice training programs on assessment of children with deafblindness and severe dis-
abilities; and 41 percent considered themselves to have inadequate training to evaluate these students. Based in part upon these identified needs, the Indiana Deafblind Services Project designed PHASES.

PHASES, was designed not only to provide training to school psychologists, but also to develop or increase “state and local capacity.” By this it is meant that PHASES would seek to identify specific psychologists around the state who represented good “investments” for training. Prospective trainees would include those who were well established within their communities, were planning to stay in their present jobs, and/or had interest in and experience with serving individuals with disabilities. Once trained, these psychologists could then serve as valuable resources for deafblind children and their families within their own counties or geographic regions, as well as mentors or partners to other school psychologists who might be called upon to evaluate children with deafblindness.

School psychologists were recruited with the support of the Indiana Association of School Psychologists (IASP). This organization, which is affiliated with the National Association of School Psychologists, is divided into seven geographic regions. Psychologists from each region were invited to apply for participation in an extensive training program, with the understanding that if accepted, the applicant would be required to complete five full days of training, spread over several sessions during a three-month period. Eventually, a total of twenty psychologists were selected for participation, two from each of the seven IASP regions, and six others from special schools or programs serving students with deafblindness and other severe disabilities.

The training program was designed to involve a combination of teaching methods, including traditional lecture, interactive discussion, panel discussion, case analyses involving reviews of actual students in Indiana schools (resulting in educational recommendations), videotape analyses, small-group and team tasks, and “homework” between sessions.

The main program presenter was Harvey Mar, Assistant Professor of Clinical Psychology in Pediatrics of the College of Physicians and Surgeons of Columbia University. Other presenters included four parents of deafblind students who took part in a panel discussion, Melanie Davis, Coordinator of the Indiana Assessment System of Educational Proficiencies of the Department of Educational Studies at Purdue University, and Karen Goehl, Director of the Indiana Deafblind Services Project.

The content of the workshop focused on non-test approaches to psychological evaluation, which emphasized evaluation of deafblind students in natural contexts and situations. This approach has been termed “contextual” or “ecological” and presumes that observations of individuals across a sample of real-life school and home activities provide the most useful information about their communication, problem solving, adaptive, social interaction, and academic skills. In this approach, the “tools” of evaluation are not formal tests, but the evaluator’s ability to identify critical educational concerns, describe communication skills and behaviors, observe competencies, recognize specific challenges, and think creatively about solutions using psychological theory and knowledge.

Focus on Practical Skills

Whereas traditional psychological evaluations might generally suggest educational programs and classroom support for students, contextual evaluations result in specific recommendations that can be directly implemented in the classroom, school, and home. For example, recommendations might focus on how to increase or improve social interaction opportunities for the deafblind student, on how to adapt lessons so that they are meaningful, on what specific communication interventions should be considered, on how to promote the student’s attention and motivation, and on how to increase participation in functional skill routines. Throughout the workshop series, the emphasis was on development and application of practical skills.

Goals and Outcomes

The primary objective of PHASES was to provide training and support to school psychologists within Indiana to enable them to conduct meaningful evaluations of deafblind students. But unlike many training programs that simply provide participants with information through lectures and discussion, PHASES was also designed to yield three demonstrable outcomes:

1. Establishment of a network of school psychologists in Indiana who could share information and resources about evaluation of students with deafblindness and other severe disabilities. This is the first large-scale effort in the country in which trained psychologists seek to expand resources and knowledge about evaluation of children with deafblindness to others within the field.

2. Production of a package of training materials for distribution to other psychologists and evaluators. These materials consisted of handouts, resource information, and videotapes of the training presentations. Two tapes were developed. The first, Assessing Children Who Are Deafblind: Conducting a Contextual Evaluation, provides an overview of a
model for assessing students with deafblindness. The second, Assessing Children Who Are Deafblind: The Parent Point of View, presents commentaries and concerns of parents of four very different children with deafblindness.

3. Positive changes in the actual practices of school psychologists during the course of training. The success of a workshop is frequently evaluated by some “satisfaction measure” completed by the participants at the end of training. The PHASES project also sought to determine whether the training provided to school psychologists resulted in any real and significant changes in their approaches to working with children and adolescents.

A questionnaire was developed to evaluate school psychologists’ practices in evaluation of children with deafblindness and other severe disabilities. The questionnaire was administered at the beginning of the first workshop session and then again after the last workshop session several months later. Responses were informally reviewed and analyzed to examine changes in practices.

For one question, the psychologists read a brief description of a student who is deafblind and has other multiple, severe disabilities. They were then asked, “How confident are you that you could do a valid and meaningful evaluation of this student?” Prior to beginning the workshop, only 2 of 21 respondents reported feeling “very” confident. The majority felt that they were “not at all” confident, and some felt that they were “somewhat” confident. By the end of the workshop series, attitudes changed. No psychologist responded “not at all” with respect to confidence level, and 9 reported feeling “very” confident.

Another question asked about the specific procedures and instruments psychologists would use to evaluate the student who was described. Prior to the workshop, psychologists often felt at a loss and reported that they would resort to the use of existing published tests. In the post test, given after training had been completed, comments of participants shifted to emphasize the use of more meaningful evaluation approaches.

Undoubtedly, the most significant change that took place over the course of the workshop was the increased sense of empathy and support for parents that each psychologist had developed. In the one-day follow-up to the workshop series, the school psychologists, nearly all of whom returned for the meeting, arose one by one to talk about their work with parents. One commented that she had made an effort to start visiting children in their homes and communities. Another reported that she viewed herself as the advocate for parents during team meetings. All of the psychologists agreed that they had come to understand and respect the challenges faced by parents of deafblind children.

PHASES was the first project of its kind. Its scope was statewide. Now—two years later—there are continuing efforts to share information among psychologists in Indiana. There is an active informal network of psychologists who participated in the training. Many of these psychologists have gained expertise and confidence to serve the needs of children within their own schools and communities.

Additional information about PHASES can be obtained by contacting the Indiana Deafblind Services Project, Blumberg Center, School of Education, Room 502, Indiana State University, Terre Haute, IN, 47809, (800-622-3035). The PHASES Training Information and Videotape Multimedia Package can be checked out through the project’s Resource Materials Center or through DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind: 800-438-9376 800-854-7013 TTY http://www.tr.wou.edu/dblink

References


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Personal Perspectives

Peggy Malloy

Personal Perspectives is a column about deaf-blind people, their families, friends, and professionals in the field. This issue features Stephanie MacFarland who, over the past twenty years, has worked as a teacher, consultant, and assistant adjunct professor in the area of deaf-blind education. Currently, she is the coordinator of a master’s level teacher training program in severe and multiple disabilities, including deaf-blindness, at the University of Arizona, and recently she was awarded a teacher preparation grant for five years. She does consulting for the Arizona Deafblind Project and is on their advisory board. I talked with Stephanie about the development of her career and her thoughts about deaf-blind education.
and the current state of personnel preparation in the field.

Stephanie knew that she wanted to be a teacher as early as elementary school. And in the third grade, when she saw the movie The Miracle Worker, about Helen Keller’s education, she felt that she would especially like to teach deaf-blind children. Her educational background includes a bachelor’s degree in elementary education from the University of Arizona, a master’s degree in educating students who are deaf-blind and multiply disabled from Boston College, and a Ph.D. in special education with an emphasis in curriculum theory, design, and development from the University of Arizona.

After graduating from Boston College, Stephanie worked for two years teaching a segregated classroom of deaf-blind children. She found the experience somewhat frustrating because teaching methods in use for deaf-blind children in the area at that time did not emphasize teaching communication or functional skills, or adapting curricula. She says, “I realized that I wanted to learn more about the importance of communication and curricula development and help establish a curricular model that would enable teachers to work more effectively with deaf-blind children.”

She decided to learn more about the teaching approach of Jan van Dijk in The Netherlands. She had first heard about the van Dijk approach while at Boston College and had been struck by its strong philosophical basis that emphasized communication, language development, and individualized planning for each student. She returned to Arizona to continue her education and ultimately ended up studying with van Dijk in The Netherlands for a year on a Fulbright scholarship.

This path led Stephanie to her involvement in teacher training. She worked for five years in Boston in the early nineties: First, as co-coordinator with Barbara McLetchie of the Boston College Teacher Training Program and then with the Perkins National Deafblind Training Project, a federally funded project to establish a model for improving educational practices. She also worked for Hilton Perkins International in Portugal and Czechoslovakia. “This was a great time in my life,” she said, “because it was wonderful to be working with so many people all focused on the areas of deaf-blindness and multiple disabilities.” The influence of others on her career and thinking is a theme that she stresses. She has been greatly influenced by many people who have been mentors to her over the years, including Sherill Butterfield, an instructor when she was at Boston College, Barbara McLetchie, Jan van Dijk, and June Downing, with whom she worked at the University of Arizona.

Stephanie has been in her current position as a professor at the University of Arizona in Tucson since 1995. She sees the current system of personnel preparation facing a number of difficulties, largely related to financial considerations. Because deaf-blindness is a low incidence disability, the number of teachers wanting to be trained in this area is small. Therefore, most universities and colleges will not independently fund teacher training programs in deaf-blindness. The programs are primarily funded by the federal government, and obtaining continued funding is an ongoing struggle. An additional difficulty, she said, is that few professors have training in deaf-blindness, and because of the lack of stable funding for existing programs, universities do not usually support tenure-track positions for these professors.

Despite these difficulties, Stephanie believes that specialized teacher training programs in deaf-blindness are essential. She doesn’t feel that generic teacher training programs provide the education that teachers need to work with deaf-blind children, and she believes that maintaining the programs will require ongoing advocacy and collaboration. One important area of collaboration, for example, is to form strong connections with universities that have training programs in severe and multiple disabilities, visual impairment, and deafness to encourage them to provide in-depth training in deaf-blindness. She says that state deaf-blind projects can play a vital role in this regard by making connections with educational institutions in their states.

When asked about important issues to consider when thinking about educating deaf-blind children, Stephanie emphasized the need for open communication between parents and teachers. “It is important for teachers to understand families’ needs and to work with each family to establish a strong link between school and home. Because the world of school and life at home are so different, teachers need to look at the home situation in a functional way and find out what is reasonable for a particular family.” Her advice to parents is to be open and honest. Collaboration and cooperation with educators is essential. She said, “I tell parents to never give up, but to keep chipping away to find the information that meets their child’s needs.”

From her first inspiration in the third grade until she was 41, Stephanie was devoted to a career in deaf-blindness. She said, “I’m still devoted to my career, but I now have another devotion since meeting my true love, getting married, and having a beautiful baby.” She uses many of the teaching techniques that she learned with deaf-blind children with her own son Joseph, now one and a half, particularly communication strategies that make concepts clear. As with
deaf-blind children, she watches and tries to see things from his point of view before trying to enter his world.

Stephanie believes that communication is at the heart of all learning and that to communicate with a deaf-blind child or any child, you need to relate to the child from his or her own perspective and stay truly aware of what is happening. She says, “If you stop being thoughtful and mindful about what you are doing, you can get into a stagnant situation.” But by careful observation, you can learn so much because, she says, “Children that I’ve taught and observed are the true teachers.”

NTAC Workshops

This year NTAC, The National Technical Assistance Consortium on Children and Youth Who Are Deaf-Blind, sponsored two annual workshops. One was for parents of children who are deaf-blind. The other was a topical workshop for state projects serving children and youth who are deaf-blind. The following reports summarize the 2002 workshops, held this past August. The parent workshop was on the topic of self-determination and assistive technology. The topical workshop was about methods for measuring and reporting implementation and child or youth outcomes as a result of technical assistance activities.

Annual Parent Workshop: A Big Success

Therese Madden Rose
Technical Assistance Specialist, NTAC

Being Self-Determined: What Does It Take? Skills + Knowledge + Attitude + Opportunity. This was the theme of the annual parent workshop sponsored by NTAC and the National Family Association for Deaf-Blind (NFADB) and held in Kansas City, Missouri, August 1-3. There were more than 125 participants, including 70 parents; state deaf-blind project family specialists; representatives from NTAC, NFADB, Helen Keller National Center, DB-LINK, and the Hilton/Perkins Program; and American Sign Language and Spanish interpreters. Thirty-three states, Puerto Rico, and the Pacific Basin were represented.

The group was welcomed by Kat Stremel, NTAC Project Director, Kathy McNulty, NTAC Assistant Project Director, and Ralph Warner, outgoing NFADB President. There were lively discussions throughout the conference. Dr. Brian Abery, from the Institute on Community Integration, University of Minnesota, led participants through a series of discussions and exercises exploring the meaning of self-determination, why it matters, and how it interacts with and affects individual and family values. Jack McCauley, Citywide Evaluation Team Facilitator for Boston Public Schools, explored the link between assistive technology and self-determination. Nancy O’Donnell, Coordinator of Special Projects at the Helen Keller National Center (HKNC) and a DB-LINK information specialist, described DB-LINK resources. Joe McNulty, Executive Director of HKNC and co-chair of the National Deaf-Blind Coalition ably connected national issues to the local level.

A lot of hard work was required in both the planning and participation phases of this event. It was a wonderful opportunity for participants who left Kansas City both exhausted and energized.

Topical Workshop: Collecting Service Implementation and Child Outcome and Impact Data

Kat Stremel
Project Director, NTAC

The purpose of the topical workshop held in Atlanta, August 27 and 28, was to help state deaf-blind projects improve the methods they use to evaluate the influence of technical assistance activities on specific outcomes for children and youth who are deaf-blind and to increase the impact of technical assistance services. More than 100 participants representing approximately 50 state projects attended. Presentations and activities included the following:

• Dr. Paula Burdette from the Mid-South Regional Resource Center provided an excellent overview of how to use a logic model method for evaluation planning. Participants then had an opportunity to use the model to create their own evaluation plans. Mark Schalock from the Evaluation Research Group Office (ERGO) at Teaching Research, Western Oregon University, helped participants develop evaluation questions based on these plans.

• NTAC staff presented a document they recently developed called Outcomes and Performance Indicators that can be used to measure and report outcomes for children and youth who are deaf-blind.

• Dr. Lizanne DeStefano, Professor of Educational Psychology from the University of Illinois at Urbana-Champaign and a consultant for the Office of
Discussion groups (cracker barrel sessions) were funded in individual, group, and systemic advocacy. Coherent national and state policies and planning are crucial.

Policy level recognition that deafblindness is more than "the sum of its parts" and requires additional focus and support; Funded individual, group, and systemic advocacy services in all states and territories focusing on the needs of people who are deafblind; Appropriate training in the area of deafblindness to ensure quality staff and services; Consistency between states in the ways they provide services.

As part of this campaign, a National Deafblind Forum was held at the Royal Blind Society in Sydney in July 2001. Forty representatives of Australian deafblindness agencies and special interest groups, as well as commonwealth and state public officials attended the event. The department of the Commonwealth Minister for Family and Community Services provided $5,000 towards the cost of organizing the forum.

The purpose of the event was to prepare recommendations to present to the National Disability Advisory Committee, which would then bring them to negotiations that are held periodically between the commonwealth and the states to consider disability policy issues under an agreement called the Commonwealth-States Disability Agreement (CSDA). The CSDA focuses on eight discrete areas of human services provision: accommodation support services, advocacy services, community support services, community access services, employment services, information services, print disability services, and despite services.

It was clear from the results of the National Deafblind Forum that no state or territory comes close to meeting the needs of its citizens who are deafblind in any of the CSDA service areas or in the areas of education, transport, and health. Representatives from all states and territories reported the lack of:

- Coherent national and state policies and planning regarding services for people who are deafblind;
- Appropriate training in the area of deafblindness to ensure quality staff and services;
- Consistency between states in the ways they provide services;
- Reliable data on the number of Australians who are deafblind; and
- Predictable results. As a first step to providing a much-needed solution to an abysmal situation, the Australian Deafblind Council (ADBC) has campaigned, in recent years, for greater political awareness of the problems faced by people who are deafblind.

Deafblindness in Australia: The State of the Nation

Dr. Michael Steer
Renwick College
Royal Institute for Deaf & Blind Children

The Commonwealth of Australia, with a population of approximately 21 million, is a federation of six states, several territories, and a number of dependencies. Its seat of national government is Canberra, a city that, like Washington, DC, is located within its own territory. According to a recent census, 18 percent of Australians have some type of disability, but there are currently no reliable data on the number of Australians who are deafblind. This is primarily because deafblindness has not been perceived as a discrete area of disability in policy negotiations between federal, state, and territory governments. A rough estimate of the number, however, is approximately 1,500 people of all ages.

Australian disability policy is comprised of commonwealth (federal) laws that apply throughout the country as well as separate disability services acts in some states and territories. Because policies have been established at different levels of government, there are often tensions, generally creative, on such issues as resource provision and service boundaries between federal, state, and territory governments. The system is loosely coordinated, and because of this, the provision of comprehensive services to Australians who are deafblind has traditionally been in the "too hard" basket or the "fall between the cracks" category, with predictable results.
• Recognition of the communication needs of people who are deafblind and their right to participate in their communities;
• Recognition of the increasing incidence of deafblindness and its associated issues as the population ages;
• Research into specific areas of deafblindness including the need for service provision and interpreters and the needs of families and advocates.

The forum evaluated the current state of services for deafblind individuals in each of the Commonwealth-States Disability Agreement service areas. Following is a summary of their findings.

1. Accommodation Support Services:
Accommodation support services address housing and independent living needs. Services to individuals who are deafblind are very limited in this area. There is an overall lack of funding and no national mechanism to guarantee a minimum level of support. Other critical issues identified include:
• The lack of choice in housing options;
• Limited information about available housing options;
• The lack of adequately trained staff, particularly staff with training in communication methods used by deafblind people;
• Limited awareness of and understanding by service providers about the needs of deafblind people and the difficulties they face living in what are often unsympathetic environments;
• The lack of assistive technology to support truly independent living;
• Problems with safety in residential homes;
• The lack of appropriate services for young people (often resulting in placement in nursing homes, psychiatric institutions, or institutions for people with intellectual disabilities).

2. Advocacy Services:
The National Disability Advocacy Program funds 76 advocacy organizations at a cost of just over $10 million a year to assist people with disabilities to participate in community life on an equitable basis and to achieve their rights as citizens. Under the Commonwealth-States Disability Agreement, advocacy is a shared responsibility of the commonwealth and state and territory governments. Currently there are no advocacy services funded specifically for deafblind people. Problems identified include:
• Poor awareness by professionals and the general public regarding the need for advocacy for people who are deafblind;
• The lack of independent advocacy services in any area that are specifically tailored to the needs of people who are deafblind;
• The lack of established structures to provide advocacy support or to train individuals who are deafblind to advocate for themselves;
• Confusion between the commonwealth and the states about their role in providing advocacy services;
• The lack of structured mentor or peer programs.

3. Community Support Services:
Community support services strengthen individuals and families by focusing support on individual needs and outcomes and by actively engaging service users, families, and careers in policy development. These services focus upon daytime activities, including post-school options. A second element of the community support services focuses on the provision of interpreters for people who are deaf or hard of hearing. Many people who are deafblind need this type of support to function in the community. Critical issues include:
• The lack of appropriately trained staff;
• The lack of individualized and gender- and age-appropriate programs;
• The inadequate availability of one-on-one support hours;
• Unequal access to general community services;
• The lack of adaptive technology and maintenance;
• Inadequate transportation assistance;
• The lack of essential broad services, such as therapy and case management.

4. Community Access Services:
Community access services target people aged 18 and older who have severe and multiple disabilities and require assistance to access community groups, activities, and places. Most people who are deafblind face real isolation due to communication and mobility issues. Critical issues identified include:
• Severely limited staffing and interpreting hours;
• Limited staff with appropriate knowledge and training;
• The lack of programs to meet the needs of individuals who require one-on-one support;
• The lack of creative programming to address individual communication needs and to encourage continued development;
• Poor transportation access;
• Services that are inflexible and unable to adapt to consumers’ timetables and needs;
• The lack of services that focus on meeting the needs of an aging population.
5. Employment Services:
Employment services promote work opportunities and job support for people with disabilities. Current employment services do not meet the needs of people who are deafblind. Critical issues include:
- The lack of opportunities for prevocational experiences;
- The lack of funded training options;
- A shortage of employment and vocational trainers with the expertise and communication skills needed to provide job training for deafblind people;
- The lack of long-term job support once an individual has obtained employment;
- The lack of adaptive technology resources;
- The lack of awareness programs for employers, managers, and co-workers in areas of particular importance to individuals who are deafblind, such as communication skills and orientation and mobility;
- The lack of support for employers;
- Limited capacity to adapt and modify workplaces;
- The lack of alternatives to employment.

6. Information Services:
Information services provide accessible information to people with disabilities, their careers, families, and professionals. This area covers specific information about disabilities, services, and equipment and promotion of community awareness. The information needs of people who are deafblind are diverse, but information is rarely available in appropriate formats. Critical issues identified include:
- The fact that governments and a wide variety of community agencies do not provide their information in accessible formats;
- The need for legal guidelines and standards that require government agencies, as well as all other agencies, utilities, and businesses to provide information in accessible formats.

7. Print Disability Services:
Print disability services produce information in alternative formats for people with disabilities who are unable to access information provided in a print medium. Deafblind people are underserved in the area of access to information. Problems identified include:
- The inability of all types of services to provide information in appropriate formats;
- The need for information that is readily available to the general public to be available on request in appropriate formats for people who are deafblind;
- The need for adaptive technology that supports access to information;
- The lack of access to qualified interpreters.

8. Respite Services:
Respite service is care provided on a temporary or intermittent basis for people who are chronically ill or disabled and who require caregiving from friends or family on an ongoing basis. Respite is a critical need for people who are deafblind and for their families. The prime focus of respite is the deafblind person, even though both the person and the family benefit.
In Australia, choices for respite care are currently limited. Needed services include:
- Options for respite provided in a variety of settings including at home, in small group homes and nursing homes, in short term placements, and in vacation settings;
- Respite services located within a reasonable distance of the deafblind individual’s home;
- Respite care that is based on individual needs but also coordinated and consistent with other services;
- Better-trained workers to provide care.

The National Deafblind Forum provided a wonderful opportunity to identify the service and support needs of Australians who are deafblind. Participants made the following formal recommendations, which were conveyed to the National Disability Advisory Committee.

1. That a coherent, combined national/states deafblindness policy be prepared and implemented. This should include the following:
   a. Recognition of the isolation of Australians with deafblindness and the associated deprivation (deafblindness is more than just “the sum of the parts”);
   b. An assertion that people with deafblindness have complex needs over and above those of the majority of people with a disability (there is specific legislation in the United Kingdom covering this issue);
   c. Recognition that there is added isolation for those who are deafblind in rural populations and a lack of staff trained in communication methods;
   d. Recognition that there is a lack of a cohesive structure in some states and territories to provide required specialized services.

2. That there must be recognition by Australian governments of the grossly inadequate provision of services for people with deafblindness in most states and territories. This is an imbalance that must be rectified.
3. That an independent advocacy service for people with deafblindness be established because the uniqueness of deafblindness restricts access to generic advocacy.

4. That a funded national training program be established to provide training courses for staff employed in the deafblindness field at certificate, diploma, and tertiary levels and to include distance education (the embryo of such a concept already exists).

5. That services in Australia be funded to provide Australia-wide information and advice on deafblindness.

6. That interpreter/communication services be included in CSDA categories and an adequate level of funding be provided for this service.

7. That service be funded in all states to enable people with deafblindness to better participate in community activities.

8. That policy be established that people with common forms of communication, where desired, be grouped together and staff with appropriate communication skills be employed and funded.

9. That there should be wide recognition that people with deafblindness need flexible respite and accommodation options that cater to their specific requirements.

10. That issues associated with aging and deafblindness (including acquired vision and hearing loss) be the subject of a major government review.

A complete report of the forum has been submitted to the National Disability Advisory Committee. The Australian DeafBlind Council awaits news of its impact.

**Editor’s Note:** Deaf-Blind Perspectives would be interested in receiving additional article submissions about the state of services for children and adults who are deaf-blind in other countries.

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**Finding Information About Assistive Technology**

Gail Leslie
Peggy Malloy

_Homemade communication boards or calendar boxes_

_Software programs that enlarge the size of words on a computer screen_

_Devices that translate typed words to Braille for telephone or face-to-face communication_

_Long white canes or adapted canes for mobility_

These examples demonstrate the range of assistive technology devices. Whether high-tech or low-tech, assistive technology is used for communication, computer skills, mobility, learning, play, independent living, and much more. Some you can make yourself. Many others are commercially available. Because needs and product options change frequently over the course of a child’s life, it is important to have access to current information. If you have questions about assistive technology (or any other topic related to deaf-blindness), contact us at DB-LINK:

800-438-9376
TTY: 800-854-7013
dblink@tr.wou.edu
http://www.tr.wou.edu/dblink

There are also a number of other organizations and agencies that have information about assistive technology for people who are disabled. The following sources provide information about specific devices, training, funding resources, and policy issues.

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**Family Center on Technology and Disability**

Academy for Educational Development
1825 Connecticut Avenue, NW, 7th Floor
Washington, DC 20009-5721
202-884-8068
E-mail: fctd@aed.org
http://www.fctd.info

The Family Center on Technology and Disability (FCTD) provides information and services related to assistive technology to support the educational needs of children and youth with disabilities. The Web site includes a database of reviews of assistive technology...
resources, such as books, newsletters, training manuals, software, and Web sites, plus a resource library containing online issues of the FCTD monthly newsletter and a number of information sheets about assistive technology. The May/June 2002 newsletter, available online, describes funding resources for assistive technology.

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State Assistive Technology Programs
RESNA Technical Assistance Project
1700 North Moore Street, Suite 1540
Arlington, VA 22209-1903
703-524-6686
TTY: 703-524-6639
E-mail: resnaTA@resna.org
http://www.resna.org/ taproject

There are 56 programs, one in every state, commonwealth, and territory of the United States, that are funded under the Assistive Technology Act of 1998. The RESNA Technical Assistance Project provides technical assistance to these programs. Services vary depending on the specific program but may include information and referral about types of products, funding, sources for repair and maintenance, equipment loan and recycling, and demonstration sites.

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Policy Information Pipeline - Funding
http://www.resna.org/ taproject/ policy/ funding/

This is a specific section of the RESNA Web site that warrants a special mention. It has current information about funding policies and strategies. Resources are organized by types of funding–IDEA, Medicare, Medicaid, and private insurance. It also provides access to particular state resources.

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ABLEDATA
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
800-227-0216
TTY: 301-608-8912
http://www.abledata.com

In a world where many assistive technology Web sites are largely a vehicle for advertising, we should always be thankful for the likes of ABLEDATA. It is a good place to locate product information, manufacturers, distributors, and resale information. You can search their online databases or call the toll-free number and talk to an information specialist. The database contains descriptions of standard market products plus information about noncommercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs. The Web site also has a library of articles, news, and a good selection of links to other resources.

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National Assistive Technology Research Institute (NATRI)
http://natri.uky.edu

The National Assistive Technology Research Institute conducts assistive technology research, translates theory and research into practice, and provides resources for improving the delivery of assistive technology services.

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American Foundation for the Blind
National Technology Program
800-232-5463
E-mail: afbinfo@afb.net
http://www.afb.org

AFB provides information about a variety of aspects of assistive technology for blind and visually impaired people, including evaluations of specific products (e.g., Braille technology, computer adaptations), a project called CareerConnect™ (a network of approximately 2,000 blind and visually impaired people who offer information and advice about job experience and assistive technology), and information about government and policy issues. AFB also has a bimonthly magazine about assistive technology called AccessWorld: Technology and People with Visual Impairments. Current issues are available by subscription, but back issues are available online.

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Alliance for Technology Access Centers
2175 E. Francisco Blvd., Suite L
San Rafael, CA 94901
415-455-4575
TTY: 415-455-0491
E-mail: ATAinfo@ATAccess.org
http://www.ataccess.org/community/centers.html

Alliance for Technology Access is a network of resource centers and associate members located in many states that provide a place to explore computers, software, adaptive devices, and telecommunications systems. Its mission is to connect children and adults with disabilities to technology tools.

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Closing The Gap
526 Main Street
P.O. Box 68
Henderson, MN 56044
Closing The Gap provides information about computer technology in special education and rehabilitation settings via an extensive Web site, a newspaper, and an annual conference. The Web site has a resource directory of hardware and software products where you can search for products.

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Jason Corning: “Yes I Can” Award Winner
Lyn Ayer
Great Lakes Area Regional Center for Deaf-Blind Education – Wisconsin

Jason Corning (Beloit, WI), received the 2002 Wisconsin Council for Exceptional Children “Yes I Can” award for Advocacy/Independent Living. Jason was one of four awardees. The ceremony took place during the Annual Awards Banquet on August 2, 2002. Jason, who is 17, is deafblind and attends the Wisconsin School for the Visually Impaired. He has shown wonderful leadership qualities in advocating not just for himself, but also for other students who are deafblind. Jason is not afraid to stand up for himself. He is independent and has the ability to communicate with people regardless of whether they know sign language or not! He finds a way to communicate. This semester Jason is working on a plan to educate others about deafblindness and thinks that this might be his vocational education plan for the semester or year. He is thinking of a career in law and has perhaps made a start already!

For Your Library

DB-LINK Information Packets

Information Packet for Graduate Students
During August, packets of DB-LINK information were sent to more than 300 students enrolled in graduate programs throughout the United States that train teachers to work with students who are deaf-blind or visually impaired. The packets contain copies of DB-LINK fact sheets, Deaf-Blind Perspectives, a publications list, a brochure, a national resources list, and Child Census information.

Information Packet for New Teachers
This information packet was developed for parents to pass on to their children’s teachers (or for teachers to request themselves). It includes fact sheets, Deaf-Blind Perspectives, lists of articles about communication, curricula, and environmental considerations, and a brochure and article that describe DB-LINK services.

If you would like to receive a copy of either of these packets or need other information, contact DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: dblink@tr.wou.edu. http://www.tr.wou.edu/dblink.


This booklet provides guidelines for creating a transition portfolio that can be used to document and communicate specific information about a student to new teachers, paraprofessionals, and support personnel. It contains numerous forms to assist in planning. To order send request and a check for $5.00 (includes shipping

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Guidelines: Practical Tips for Working and Socializing with Deaf-Blind People (Revised Edition)


An expanded and updated edition of a book that was originally published in 1994. The purpose of the book is to serve as a practical guide to help readers explore the effect of deaf-blindness. It presents ideas based on experience and observations and offers practical suggestions and guidelines that can be applied to specific situations. Available from Sign Media, Inc. Phone: 800-475-4756. Fax: 301-421-0270. E-mail: signmedia@aol.com. http://www.signmedia.com. Cost: $24.95.

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National Curriculum for Training Interpreters Working with People who are Deaf-Blind


A result of the National Interpreter Education Project, this curriculum consists of 9 in-service training modules and a four-credit college course. It is available from the National Clearinghouse of Rehabilitation Training Materials, Oklahoma State University. Phone: 800-223-5219. Fax: 405-624-0695. Order number: 746.050. Cost: $92.70.

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Problem Solving Skills


Design to Learn Projects has recently revised a set of instructional materials developed for children who are deaf-blind that are used to evaluate the cognitive skills of nonverbal children with severe disabilities as demonstrated through their interactions with the physical environment. Includes School Inventory of Problem Solving Skills (SIPSS), Home Inventory of Problem Solving Skills (HIPSS), and Problem Solving for Children with Multiple Disabilities: Guide to Assessment and Teaching Strategies. Available from Design to Learn Projects. Phone: 888-909-4030. Fax: 503-238-7010. Email: design@ohsu.edu. http://www.designtolearn.com.

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Self-Determination for Children and Young Adults Who Are Deaf-Blind


An NTAC briefing paper on the topic of self-determination as it relates to deaf-blindness. Available on the Web (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.

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Strategies for Inclusion: A Handbook for Physical Education


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Understanding Deafblindness: Issues, Perspectives, and Strategies.


A comprehensive 2-volume curriculum for parents, intervener, and service providers working with children and young adults who are deaf-blind. Aspects of deaf-blind programming covered include communication, concept development, vision, hearing, touch, sensory integration, intervention, family issues, physical education, additional disabilities, orientation and mobility, community support, and evaluation. Individual chapters were written by professionals with expertise in their respective subject areas. Available from Hope Publishing, Inc. Phone/ Fax: 435-245-2888. E-mail: hope@hopepubl.com http://www.hopepubl.com. Cost: $160.00

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Understanding Usher Syndrome: An Introduction for School Counselors


Provides information and resources about Usher Syndrome for counselors and educators serving school-age students. It includes basic practices for schools, sections about the effects of Usher Syndrome on communication and career planning, and personal accounts. Available from HKNC Information Specialist, 111 Middle Neck Road, Sands Point, NY 11050. Phone: 516-944-8900, ext. 326. TTY: 516-944-8637. E-mail: hknccinfo@rcn.com. Cost: $15 (includes shipping and handling).
Conferences and Events

Texas Symposium on Deafblindness
February 7-8, 2003
Austin, Texas

This event will bring together families of infants and school-aged children with deaf-blindness and the professionals and paraprofessionals who serve them. They will have the opportunity to hear a host of experts discuss various aspects of programming for children and young adults with deafblindness. Out-of-state participants are welcome (funds are not available from the Texas Deafblind Project to assist these individuals with conference costs).

Contact:
Beth Rees
Texas School for the Blind and Visually Impaired
512-206-9103
E-mail: bethrees@tsbvi.edu
http://www.tsbvi.edu/Outreach/vi.htm

Annual Conference on Disabilities PAC RIM 2003
February 10-11, 2003
Honolulu, HI

The theme this year is “Collaboration and Change: A Future of Choices for Mind, Body, and Spirit.” Persons with disabilities, family members, researchers, and service providers join policy-makers and nationally recognized speakers to learn from each other and to share resources for communities to fully accept and support persons with disabilities.

Contact:
Center on Disability Studies
University for Excellence
1776 University Avenue, UA 4-6
Honolulu, HI 96822
808-956-9810
E-mail: cds@hawaii.edu
http://www.cds.hawaii.edu

Vision Loss in the 21st Century: Everybody’s Business
February 19-22, 2003
Beverly Hills, California

An international symposium addressing the impact and understanding of the challenges of vision loss on society. Co-sponsored by the American Foundation for the Blind and the Foundation for the Junior Blind.

Contact:
American Foundation for the Blind
800-232-5463
E-mail: communications@afb.net or info@fjb.org
http://www.visionloss2003.org

CSUN Annual International Conference: Technology and Persons with Disabilities
March 17-22, 2003
Los Angeles, California

Contact:
Center on Disabilities
California State University, Northridge
18111 Nordhoff Street, Bldg. 11, Suite 103
Northridge, CA 91330-8340
818-677-2578 V/TTY
Fax: 818-677-4929
Email: ctrdis@csun.edu
http://www.csun.edu/cod

Western Symposium on Rehabilitation and Deafness
April 9-11, 2003
Seattle, Washington

The theme is “Partners in Progress: Improving Employment and Education Outcomes for Individuals who are Deaf, Hard of Hearing, Late Deafened, and Deaf-Blind.”

Contact:
Cheryl D. Davis
Regional Resource Center on Deafness
Western Oregon University
345 N. Monmouth Ave.
Monmouth, OR 97361
503-838-8642 (V/TTY)
Fax: 503-838-8228
E-mail: davisc@wou.edu
http://www.wou.edu/wrocc

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
Phone: 301-495-4403
TTY: 301-495-4402
Fax: 301-495-4404
E-mail: tomjill@juno.com or mcnamara@aadb.org

International CHARGE Syndrome Conference
July 25-27, 2003
Cleveland, Ohio

Check the Website or call DB-LINK (800-438-9376; 800-854-7013 TTY) for updates.
**Announcements**

**Call for Art Work**

**Helen Keller International Art Show**

The Helen Keller International Art Show sponsored by the Council for Exceptional Children Division on Visual Impairments and the University of Alabama at Birmingham Vision Science Research Center invites youth who are deaf-blind, blind, or visually impaired to submit art work. Students may select the preferred art medium. The contest is open to students of all ages. Each school system may submit up to 7 pieces of art. Art should be submitted by January 13, 2003. The winning entries will be exhibited, beginning with the CEC International Conference in Seattle, April 2003. For more information or to obtain entry forms, contact UAB Vision Science Research Center. Phone: 866-975-0624. Fax: 205-934-6722. E-mail: Msanspree@care.opt.uab.edu.  DB-LINK (800-438-9376 or 800-854-7013 TTY) can also provide copies of the entry form.

**Digital Library Project**

This project is creating an online sign language library of American Sign Language (ASL) signs for terms that are used in academic subject areas. A biology module has been completed and geography and math modules are in development. Each vocabulary word has a video clip demonstrating how the word is signed, followed by a demonstration of how it is used in a sentence. Written descriptions of the signs are also provided. The Digital Library Project is one of the services of NEEDS Outreach, a non-profit educational organization serving students with disabilities in San Diego and Imperial counties, California.

The biology module can be accessed on the Web at http://www.needsoutreach.org/Pages/sl.html. For more information about the project contact Barbara Pflaum, Technology Coordinator, Needs Outreach, 4833 Doliva Drive, San Diego, CA 92117. Phone: 858-573-8895. E-mail: bpflaum@mail.sandi.net.

**Including Students with Deafblindness in Large Scale Assessment Systems**

This is a three-year project to study how students with deaf-blindness fare in large-scale assessment systems. It is being conducted by the Interdisciplinary Human Development Institute-UCE at the University of Kentucky. Issues being studied include: exemption rates from large-scale assessments for students who are deaf-blind, how student scores compare with those of their peers both with and without disabilities, how accommodations are determined and implemented, and the extent to which teachers of students who are deaf-blind modify their curricular and instructional practices to align with the assessment. More information is available at the project Web site: http://www.ihdi.uky.edu/kydb-research.

**Alstrom Syndrome International**

Alstrom Syndrome International is an organization for families, physicians, educators, and researchers interested in Alstrom Syndrome. There is a quarterly family newsletter and international family conferences. ASI also sponsors medical conferences internationally. Address: 14 Whitney Farm Rd., Mount Desert, ME 04660. Phone: 800-371-3628. E-mail: jdm@jax.org. Web http://www.jax.org/alstrom.

**DB Techies E-mail Mailing List**

DB Techies is a mailing list that was started for deaf-blind people by a deaf-blind person. It’s also for blind, Deaf, and partially sighted people. DB Techies mailing list is a place to talk about new equipment, technical troubles, and new products.

To subscribe, send an e-mail to: dbtechies-subscribe@topica.com or go to http://www.topica.com.lists/dbtechies.
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☐ Administration (e.g., Dept. of Ed., project director) ☐ Teacher trainer
☐ Service provider (e.g., social worker, group home) ☐ Government personnel
☐ Technical assistance provider ☐ Medical professional
☐ Higher education teacher/researcher ☐ Other ____________________________

Please send my copy in:

☐ Grade 2 braille ☐ Large print
☐ Standard print ☐ ASCII ( Disk E-mail)

Mail to: Deaf-Blind Perspectives
Teaching Research Division
345 N. Monmouth Ave. Monmouth, OR 97361
or call Randy Klumph (503) 838-8885, TTY (503) 838-8821,
Fax: (503) 838-8150, E-mail: dbp@wou.edu

All issues of Deaf-Blind Perspectives are available on the Internet at www.tr.wou.edu/tr/dbp

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