Seeing The Humor In It All
Living With Deafblindness

Ronald Malcolm

It’s interesting how many small things we take for granted. I never realized that there were once many parts of my day that I never gave a second thought to. As a deafblind man, I experienced my deafness first and then became blind several years ago. Before I lost my vision I was able to watch a platform interpreter with ease. Glancing at my watch to see what time it was, was effortless. Reading my TTY or the captioning on the television was just an ordinary part of my day. Running to the store to pick up a simple item such as a gallon of milk was simply a part of everyday life.

Yet, my everyday life began to change when several years ago my vision began to rapidly decrease. I actually went to see my eye doctor because I thought I needed a stronger prescription. Looking back, I now recognize many of the warning signs that there was a problem with my eyes. However, a visit to the eye doctor always seemed to be put on the back burner so I could cope with my already busy schedule.

Shortly after my visit with the eye doctor my regular life came to an abrupt halt. This was followed by numerous visits to a neurologist, MRIs, Cat Scans, and of course the ever-favorite spinal taps. Just when I thought I would never know what was wrong, I received the diagnosis. My doctors told me that I had optic neuritis as well as middle artery cerebrovascular eye disease. Shortly after the diagnosis, two things occurred. The first was that my vision began to rapidly deteriorate. My peripheral vision reduced to a seven-degree field in my right eye and a five-degree field in my left eye and my night vision disappeared. The second thing that occurred is that my life came to a screeching halt in terms of my independence.

My struggle to regain my independence began to seriously affect my day. Orientation and mobility lessons began at 6 a.m. I studied braille during my lunch hour. I took computer training for the blind in the evenings and on the weekends. Combine all of this with my full-time job as a school administrator, my part-time job as a university professor, my involvement with my doctoral program, my commitment to my wife and dealing with the needs of my five children—I was beginning to feel overwhelmed.

After several months of training I began to feel that my life was mine again. I could read a braille book to my children at bedtime. I could walk my son to his karate lesson. I had learned several bus routes after realizing that driving a car was no longer an option.

I had some wonderful assistance from many well-meaning individuals. However, I was person who had always prided himself on his ability to be independent—it was difficult to accept such assistance. Yet, in time I learned.

One Christmas, I traveled out of state to visit relatives. Three of my younger children were with me. My only daughter Chelsea, four at the time, was playing in Grandpa’s garage with her brother Joel when she fell and broke her arm. At the hospital they would not place her arm in a cast due to the swelling. I was told that we would need to wait three days before the arm could be put in a cast. Before then, we had to fly back home to Las Vegas.

When we arrived in the Las Vegas airport, I was nervous about getting Chelsea through the airport crowds with-
out having her arm bumped. Her swelling had reduced and my primary goal was to get her through the airport and to a hospital to have her arm put in a cast.

My son and daughter always hang onto the pockets of my pants when we walk. This allows me to use my cane but also be able to feel that my children are still with me. In my rush to get through the airport, I took a wrong turn and ended up going through the line that needed to walk through the metal detector. I should have turned around but not wanting anyone to bump into my daughter with a broken arm I figured it would be just as quick to continue on. Little did I know what confusion it would cause.

As I approached the metal detector, I had slipped my mind that my cane would set off the alarm. As I backed up to re-enter the detector, I suddenly felt the hands of my two children let go of my pockets. I immediately began to panic when I could not find my children. An attendant had motioned to my children to go through the detector without realizing that I was deafblind. The attendant, seeing that I was panicking, began to try to communicate with me. Of course, I couldn’t understand what this woman was trying to say to me. At this point a line of other individuals was forming behind me, all eager to catch their awaiting flights. As the lady continued to try to speak to me, I finally felt the hands on either side of my pockets. Knowing my children had returned, I regained my composure. The persistent lady was now standing directly in front of me. Finally, I understood what she was saying. In order to get me through the metal detector, she loudly said to me, “Sir…please pass me your WAND!” Well, I had heard my cane called a lot of things in my day but never a “WAND.”

At this point, we were almost finished with our trip through the airport. I had great hopes of getting my daughter to a local hospital. The last thing we had to do was go down an escalator and then go through a door to wait for my wife to pick us all up. As we approached the escalator, I reminded my children to hold onto my pockets. I then instructed them that we’d walk through a door and their job was to identify their mother so we could all go home. Sounded simple enough. Everyone seemed to understand his or her roles. Yet, as a deafblind adult, I have learned that nothing is easy.

As we stepped onto the escalator, I felt a hand pull away from my pocket. My son had become spooked by the escalator and let go. So, now I was carrying my luggage and a cane in one hand, carrying my daughter with a broken arm in my other arm while I attempted to go “up” the “down” escalator. As I tried to get to the top of the escalator, I noticed a person standing next to my son at the top of the escalator. Due to my limited vision I couldn’t see the person clearly. As I continued to attempt to go up the escalator I began to call out to the person. I told him to take my son’s hand and help him get on the
escalator. I repeated myself several times. I became increasingly frustrated that this person was refusing to offer assistance. I continued to call out for help but to no avail. I mean after all, couldn’t this person see what kind of a situation I was in?

Finally, I reached the top of the escalator. I situated both my children, put down my luggage, and took a deep breath. Then I turned in total frustration to the man standing next to my son. I wasn’t sure what I was going to say to this individual. After all, he had blatantly ignored my requests for help. As I approached the man, I got the surprise of my life. The man I had been yelling at to take my son’s hand to help him get on the escalator—had NO arms! Of course, with my limited vision, I was not able to see this as I was trying to get up the escalator. In return the armless man had no idea the lunatic yelling at him was deafblind. When we both realized what had happened, there was nothing left to do but laugh. In all the planning for the day’s events I could never have predicted the string of events that I would be involved in for that day. I mean, how often does a deafblind guy yell at an armless man on a moving escalator.

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The 1997 Amendments to the Individuals with Disabilities Education Act

Part 1: Changes to Parent Participation, Evaluations and Reevaluations, and the IEP Process

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The Individuals with Disabilities Education Act (I.D.E.A.) amendments of 1997 bring major changes to special education. To many, these changes are as revolutionary and sweeping as the original passage of the Education of All Handicapped Children Act in 1975. If fully embraced by those charged with their implementation, the amendments can enhance the lives and independence of all students, disabled and nondisabled alike. The 1997 amendments to the I.D.E.A. are not simply technical; indeed they have a) reconceptualized the role of parent participation in a child’s special education; b) redefined the evaluation, reevaluation, and IEP team process; and c) linked the IEP to the general education curriculum. The amendments call for planning and program development that can result in greater inclusion of students into the routine of general education, and they hold the potential to provide the supports and systems change needed to make this inclusion successful for all.

A comprehensive review of the I.D.E.A. ‘97 and its subsequent changes is beyond the scope of this article. The discussion in the following pages is not intended to be all encompassing. Rather, it is the first of a series of articles, that will conclude with a discussion of the re-authorization’s implications for children and students who are deaf-blind and their families. The intent of this first article is to summarize those changes that immediately affect students, their families, and teachers. These include parent participation; evaluation, reevaluation, and eligibility determination; and changes in the IEP process and content requirements. Other changes will be presented in future issues.

Parent Participation

Many of the changes in I.D.E.A. ’97 recognize the important role parents play in the development and education of their children. In short, Congress has increased the inclusion of parents in all aspects of
their child’s special education. Specifically recognized is the need for local education agencies to include parents in the initial evaluation and subsequent reevaluations of their child, as well as in the eligibility determination and placement process. Prior to the 1997 amendments, parents were involved in the evaluation and reevaluation of their child “whenever appropriate” and often at the discretion of the multidisciplinary team or local school district policies. The changes brought about by the 1997 amendments now require that the child’s parents are members of the multidisciplinary team that evaluates and determines their child’s eligibility for special education. This involvement is not cursory, nor is it limited to a passive role. For a child referred for an initial special education evaluation and eligibility determination, parents participate in the design of the evaluation process, provide information related to their child, and participate on the team that determines if their child is a child with a disability as defined in the I.D.E.A. Parents must also be provided with a copy of the child’s evaluation report and the documentation used to determine the child’s eligibility.

During the reevaluation process, parents are considered to be equal members of the multidisciplinary team which reviews existing evaluation data, including evaluations and information provided by the parents to determine what additional data, if any, are required to determine whether a child continues to have a disability. Again, parents must be provided with a copy of the child’s evaluation report and the documentation used to determine the child’s eligibility.

**Changes in Initial Evaluations, the Reevaluation Process, and Eligibility Determination**

The changes required by the amendments related to initial evaluations, reevaluations, and eligibility determination are limited not only to increased parent participation, but significantly change the process previously required of schools and local education agencies.

**Initial Evaluations**

Similar to previous law, before a student is deemed eligible to receive special education and related services, an individualized and comprehensive evaluation of the child must be conducted. The purpose of this evaluation has been expanded by the re-authorization and now includes the following determinations:

- Whether or not the child is a “child with a disability” as defined by the I.D.E.A.
- The child’s present level of educational performance
- The specific educational needs of the child

The requirement that parents of the student provide their informed consent before the evaluation is initiated remains, as do the requirements that the evaluation be nondiscriminatory and use technically sound evaluation tools. However, the re-authorization additionally requires that the local education agency use a variety of assessment instruments and that the evaluation include the collection of functional, relevant, and developmental information about the child. This information must assist the team in determining eligibility of the child for special education and in determining the educational needs of the child. The local educational agency must now consider information provided by the parent, as well as existing relevant evaluations and classroom observations.

The major additions to the initial evaluation of a student address:

- Consideration of any existing evaluation information that is available and appropriate
- Increased parent participation, input, and involvement
- Activities used not only for determining the child’s eligibility for special education, but also that assist the team in determining, planning for, and meeting the child’s educational needs

**The Reevaluation Process**

Prior to the re-authorization of the I.D.E.A., all students identified for special education were required to be reevaluated at least every 3 years. This reevaluation was to determine the student’s continuing eligibility for special education.

In revising the reevaluation requirements, Congress recognized that the previous process had become an intensive paperwork process, often driven by compliance and legal concerns, rather than the interests of the child. The revisions established by Congress do away with unneeded testing and assessment if the child’s disability has not changed. The intent is to reduce the time and expense associated with the reevaluation process. Under the new amendments, local educational agencies must now reevaluate identified students:

- Whenever conditions warrant a reevaluation
- If the child’s parent or teacher requests a reevaluation
• At least every three years

At first glance, it may appear that this change differs little from old law and actually may increase the frequency and complexity of the reevaluation process. However, in practice the amendments have substantially altered the process used in reevaluating students.

New reevaluation requirements call for the student’s Individualized Education Program (IEP) team, other qualified professionals as appropriate, and the student’s parents to review all existing evaluation data. This review must include evaluations and information provided by the child’s parents; current classroom-based assessments, data, and observations; and teachers’ and related service providers’ observations and data. Based on this review, the IEP team must then determine if any additional information is needed in order to decide:

• Whether the child has, or continues to have, a particular category of disability as defined by the I.D.E.A.
• The student’s current present levels of educational performance
• The student’s continued need for special education and related services
• Any necessary additions or modifications to the student’s special education and related services to assist the student in meeting the IEP annual goals and for participating in the general curriculum

If during this review, the team determines that existing data are sufficient and that no additional data are needed, the school district must contact the parents to inform them of the decision and to notify the parents of their right to request an assessment. If additional assessment and testing are needed or requested, I.D.E.A. ‘97 now requires informed parent consent prior to the initiation of the additional testing. If the parents do not respond to the informed consent request, local education agencies can initiate the reevaluation process only after demonstrating that it has taken reasonable measures to obtain the consent and the child’s parents have failed to respond to their request. The law also now requires that the reevaluation process be used to determine that a student is no longer eligible for services as a child with a disability as defined by the statute.

As with initial evaluations, reevaluation must also include the review of information from a variety of assessment tools and strategies to gather relevant, functional and developmental information, including information provided by the student’s parents, not only to determine a student’s eligibility for services, but also to assist the team in determining, planning for, and meeting the child’s educational needs.

Eligibility Determination

Prior to re-authorization, parents were not required to be members of the team making decisions related to their child’s eligibility for special education. I.D.E.A. ‘97 requires that parents be included by local education agencies in all decisions related to their child and that they be included on the team of qualified professionals determining their child’s eligibility.

The I.D.E.A. ‘97 also has established a “Special Rule for Eligibility Determination.” Succinctly stated, this rule requires that a student not be determined to be a child with a disability if the determining factor is a) a lack of instruction in reading or math; or b) a student’s limited English proficiency.

For both initial evaluations and reevaluations, the law also requires that the local education agency provide parents with a copy of evaluation reports and documentation of their child’s eligibility determination.

Changes in the Individualized Education Program (IEP)

Many of the most significant changes in the I.D.E.A. ‘97 revolve around the IEP team membership, the content of the IEP, and the IEP process. The IEP remains the cornerstone of educational planning for students with disabilities. Traditionally, the purpose of the IEP has been to identify the specific special education and related services a student needs in order to receive a free, appropriate public education. The I.D.E.A. ‘97 expands on this purpose, however, by enhancing the IEP’s relationship with the regular education curriculum and by increasing the involvement of regular educators in the development and implementation of IEPs.

Team Membership

The membership of the IEP team is similar to that required by previous law. Although parents were always involved in the development of their child’s IEP, the amendments now enhance the parent’s role on the IEP team and the importance and value of their input. The local education representative must now also be knowledgeable about the general education curriculum, as well as special education and the resources available. At least one regular education teacher is also now required to be on the student’s IEP team if the child is, or might be,
participating in the general education environment. The previous law required regular education teacher participation only for students with learning disabilities.

I.D.E.A. ‘97 also delineates the role of the regular education teacher. The new statute specifically requires that the child’s regular education teacher (as appropriate) participate in the development of the IEP. This participation includes determining the following:

- Appropriate positive behavioral interventions and strategies
- Supplementary aids and services
- Program modifications
- Supports for school personnel

Revised IEP Content Requirements

The required content of the IEP has been dramatically changed and now shows increased emphasis on the student’s inclusion in the regular education environment and the relationship between the student’s educational program and the regular education curriculum.

In reviewing the content requirements of the IEP established in I.D.E.A. ‘97, it is apparent that there is a blending of the old with the new. That is, although the concepts of present levels of educational performance, the establishment of annual goals and short-term objectives, and the dates for the initiation and duration of services remain, they each must now relate to the impact of the student’s disability on his ability to be involved with and progress in the general education curriculum. Teams must now address the modifications and supports that are needed for school personnel and the student, which allow the student to be involved in the general curriculum, extracurricular and non-academic activities, and state-wide and district-wide assessments of student achievement. The IEP must now also include a description of how the student’s progress will be reported to parents. This reporting must be done at least as often as parents of nondisabled children receive reports of their children’s progress.

Previously, IEP teams were simply required to identify the student’s participation in regular education. Teams must now explain and justify the extent to which a student will not participate in the regular classroom and activities with nondisabled peers.

Specifically, the IEP must now include the following:

- A statement of the student’s present levels of educational performance. This includes how the student’s disability affects involvement and progress in the general education curriculum. If the child is of preschool age, this statement must address how the child’s disability affects participation in appropriate activities.
- A statement of measurable annual goals, including benchmarks or short-term objectives, related to
  - Meeting the child’s needs that result from the disability and enabling the child to be involved and progress in the general education curriculum
  - Meeting each of the child’s other educational needs that result from the child’s disability
- A statement of the special education, related services, and supplementary aids and services to be provided to or on behalf of the child. This includes the program modifications or supports for school personnel that will be provided for the child to
  - Advance appropriately toward attaining the annual goals
  - Be involved and progress in the general education curriculum and to participate in extracurricular and nonacademic activities
  - Be educated and participate with other children with disabilities and nondisabled children
- An explanation of the extent of nonparticipation, if any, with nondisabled children in the regular class and activities
- A statement of any individual modifications needed for the child to participate in the administration of state- or district-wide assessments of student achievement, or a statement of why the student will not participate in the assessments, including how the child will be assessed.
- The projected date for beginning the described services. This must include identified modifications and the anticipated frequency, location, and duration of the services and modifications
- Beginning at age 14, a statement of the student’s transition service needs. Beginning at age 16, a statement of needed transition services. Also, a statement informing the student of any rights that will transfer to him or her upon reaching the age of majority must be included in the IEP at least 1 year before the student reaches the age of majority as defined by state law.
- A statement of how progress will be measured and how the parents will be regularly informed of the student’s progress.
Special factors which the IEP team must consider have also been added by the 1997 amendments:

- Appropriate strategies, interventions and supports for a student whose behavior impedes his or her learning, or the learning of others
- IEP-related language needs for students with limited English proficiency
- Instruction in braille for students with visual impairments or those who are blind, if appropriate
- Communication needs of a student who is deaf or hard of hearing, including the student’s language and communication needs, opportunities for direct communication with peers and professionals in the child’s language and communication mode, and opportunities for direct instruction in the child’s language and communication mode
- Whether the student requires assistive technology devices and services.

Review of the IEP

The re-authorization retains the requirement that IEPs be reviewed at least annually and additionally requires the team to address the results of a) any reevaluations; b) a student’s lack of expected progress toward the IEP’s goals and the general curriculum when appropriate; and c) information provided by the parent whenever the IEP is reviewed. New law also requires the student’s regular education teacher, as appropriate, to participate in IEP reviews and revisions.

The second article in this series (in a future issue of Deaf-Blind Perspectives) will discuss mediation and student discipline, one of the more complex changes in the re-authorization of the I.D.E.A.—ED.

What is Self-Determination?

Self-determination is the power to make choices that reflect personal preferences, interests, and values, the prerogative to have control over one’s own life, and the freedom to develop a vision for the future and to have that vision respected by others. A sense of self-determination is necessary for the development of individual identity. It is a crucial catalyst of independence and autonomy, and a fundamental component of quality of life. Characteristics of self-determination include the following:

- An awareness of personal preferences
- The ability to set goals
- The ability to use the skills one possesses to achieve goals
- The ability to evaluate progress toward a goal and learn from experience

Being self-determined does not mean that one is completely independent or autonomous. People with high levels of self-determination recognize the importance of interdependence and know they need others in their lives.

Research-to-Practice: Facilitating the Self-Determination of Youth and Young Adults With Deaf-Blindness

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Those who know children and youth who are deaf-blind share the goal that they lead the highest possible quality of life. In order to meet this goal we must provide support and education that will enable each individual to develop a vision for the future, to speak for himself or herself, and to effectively communicate his or her preferences, values, and interests.

Many persons with disabilities, including children and youth who are deaf-blind, are not encouraged to dream about the future. Instead, their futures are often determined by others on the basis of what is available rather than what is needed to make their dreams a reality. Enhanced self-determination provides children and youth with the tools to dream about their futures and set goals for themselves. It also actively promotes those capacities often referred to as self-advocacy that increase the likelihood that their dreams will eventually be realized.

Currently, a project designed by the author and Ann Eggebeen at the University of Minnesota is studying the issue of self-determination in order to enhance understanding of this important issue and develop educational materials to support and promote self-determination in deaf-blind youth and young adults. The purpose of this article is not to provide answers to all the questions that individuals who are deaf-blind and those who love and support them may have about self-determination, but rather to raise the issue, provide a definition, and stimulate thought about new ways to support its development in deaf-blind children and youth.
Why is Self-Determination Important?

The levels of self-determination exercised by some children and youth who are deaf-blind are considerably below their capabilities. Upon reaching adulthood they are likely to find themselves living, working, and socializing in settings they did not choose and that do not reflect their preferences or meet their needs. Enhanced self-determination can help avoid this outcome. Specific advantages of self-determination include the following:

Improved Learning

When children and youth come to believe that they have the ability to control their lives, they become partners with parents, teachers, and others both in the overall learning process and in exercising personal control. This increases their motivation, focus, and persistence and enhances the quality of their learning both in and outside of the classroom.

Enhanced Community Participation

When one talks with children and youth who are deaf-blind, it becomes clear that these are young people who have an intense desire to participate in and be a part of their communities. It is also obvious that many have an extreme distaste for being placed in the position of being dependent upon others. Self-determination skills directly enhance the ability of young persons to live independently within the communities of their choice, maintain valued employment, and develop circles of friendship and support. When children and youth who are deaf-blind are encouraged to take charge of their lives, they are also being encouraged to live as fully included members of society both in the present and the future.

Increased Personal Responsibility

The best way to teach children about responsibility is to present them with opportunities to make decisions and then allow them to experience the outcomes of their choices. In this manner, they learn to exercise control within the home, school, and community, taking into consideration not only themselves but also others around them.

Higher Self-Awareness and Self-Esteem

Students with disabilities, especially those who are deaf-blind, are often not given the opportunity to take risks, try new things, and experience the joys of success or the lessons of failure. Self-determination encourages individuals to discover their own capacities first-hand, to understand, adjust to, and accept the challenges created by their disability, and to build upon their unique talents and strengths.

How Can Self-Determination Be Promoted?

Promoting self-determination can be viewed as a process in which parents and professionals provide supports so that, as children develop, they have opportunities to gradually take greater control over their lives. These supports could entail a wide variety of resources based upon the age and unique needs of the child. Some examples include the following:

- Interveners
- Augmentative communication technology
- Mobility training
- ASL instruction for parents and family members

Most importantly, however, we need to provide children and youth who are deaf-blind with ongoing opportunities to exercise personal control so they can acquire and refine the capability to take charge of their lives. Given appropriate supports and the opportunity to gradually exercise greater control as their ability to take responsibility for their decisions increases, they will create personal visions for the future, make their own decisions, independently problem solve, and learn to advocate for themselves and others.

In summary, making it possible for children and youth who are deaf-blind to take greater control over their lives will not necessarily be an easy task. Many barriers must be overcome, including those created by the individual’s limited hearing and vision and by the manner in which we currently educate persons with disabilities. Self-determination is a lifelong process to which parents and professionals, can make great contributions. By seeking new ways to support the developing self-determination of children and youth, while keeping in mind the unique skills and abilities each possesses, parents and professionals can effectively prepare young persons who are deaf-blind for their lives as adults. Supporting children and youth to build the capacities that will allow them to take greater control over their lives as they approach adulthood should be one of the foremost goals of educators and parents.
Finding A Summer Camp  

Peggy Malloy

Each spring, DB-LINK receives numerous requests regarding how to find information about summer camps. The resources and articles listed below will help you locate camps and also learn more about issues to consider when choosing a camp. While there are few camps available that specifically serve deaf-blind children, there are many that serve children with special needs. You may also want to locate regular camps in your community and discuss with those that interest you how they can best accommodate the needs of a particular child.

Agencies

DB-LINK

DB-LINK usually has listings for several camps that serve deaf-blind individuals in our resource database each spring. Some serve deaf-blind children and teens, while others are for deaf-blind adults. If you are aware of camps that serve either deaf-blind children or adults, please let us know so that we will have this information available to share with others.

If you need assistance finding or accessing any of the resources listed in the remainder of this article, contact DB-LINK.

State and Local Agencies

Check with the following organizations to see if they have information about camps in your area:

- State deaf-blind projects
- National Family Association for Deaf-Blind (NFADB) regional directors
- Local parent training & information centers
- Support or advocacy organizations for deaf-blind people in your state

Printed Camp Guides

Guide to ACA-Accredited Camps - A directory of over 2,000 camps throughout the United States. Cost: 19.95 (includes shipping and handling). This guide is also available in many public libraries and on the American Camping Association web site (see below).

American Camping Association
Attn: Guide Sales
5000 State Road 67 North
Martinsville, IN 46151-7902
(800) 428-CAMP (2267)

Camps for Children With Disabilities - A brochure containing tips for choosing a camp and a list of Easter Seal Societies with Residential Camping Programs.

National Easter Seal Society
230 West Monroe Street
Chicago, IL 60606
(312) 726-6200
(312) 726-4258 (TTY)
http://www.easter-seals.org

Or contact the Easter Seal Society in your community.

Summer Camps for Children Who Are Deaf or Hard of Hearing - A list of camps, family learning vacations, and remedial clinics for deaf and hard-of-hearing children.

National Information Center on Deafness (NICD)
Gallaudet University
800 Florida Avenue, NE
Washington, DC 20002
(202) 651-5051
(202) 651-5052 TTY
nicd@gallux.gallaudet.edu
http://www.gallaudet.edu/~nicd

Special Camp Guide: Camps and Summer Programs for Children with Special Needs - Lists residential camps in the Northeastern United States and day programs in the 5 boroughs of New York. A new edition will be available in February 1999. Cost is 20.00, plus 4.50 shipping and handling. Resources for Children with Special Needs will also be holding a Special Camp Fair in New York City on February 7, 1999 at the American Red Cross, 150 Amsterdam Avenue, between 66th and 67th Streets from 10 a.m. to 3 p.m., where the guide will be given away for free.

Resources for Children with Special Needs, Inc.
200 Park Avenue South
Suite 816
New York, NY 10003
(212) 677-4650
Camp Guides On The World Wide Web

American Camping Association
http://www.aca-camps.org

Easy-to-search database contains information on more than 2000 camps accredited by the American Camping Association. Includes camps that serve individuals with disabilities. Many of these camps have their own web sites that you can browse for additional information.

Kids' Camps
http://www.kidscamps.com

Provides way to search for camps by a number of different categories including residential camps, day camps, and special needs.

Super Camp Guide
http://family.go.com/Features/family_0000_01/dony/Camps/Camps.html

For Further Reading


Provides guidelines and suggestions for parents to consider when choosing a summer camp for their child with disabilities.


Discusses strategies that allow children with special needs to attend regular summer camps. Suggests reviewing camp literature for indications of accessibility and talking personally with staff to see what kind of experience the camp has had including children with disabilities. Emphasizes the importance of communication throughout the registration process as well as during and after camp. Includes specific ideas for overcoming environmental barriers and ways to include all children in all aspects of the experience.


Lists tips for finding a good camp for deaf children, and important questions to ask the camp director. Included is a directory provided by Gallaudet University, listing 1997 summer camps for children who are deaf or hard of hearing.

Books For Parents and Families

Gail Leslie

There are numerous books written from many different perspectives on the realities of living with a disability. DB-LINK is often asked to provide a list of titles useful for parents and families. Given the number of books and the difficulty in recommending just the right piece of writing for just the right set of circumstances, we rely on lists published regularly by disability related organizations or book dealers. What follows here are sources for current lists and catalogs of books that parents or service providers might find useful.

Blind Children’s Fund Publications List - A catalog of informational books for parents and teachers. For a copy of the catalog: (517) 347-1357 or email: blindchfnd@aol.com.

Family Village Bookstore: Reading and Resource Lists - Online bookstore provides lists of current books by subject.

Good Books About Disabilities: Special Needs Project Master Catalog - An extensive catalog of books for both children and adults. The Project not only produces the list, but sells books and will locate specific titles for consumers. For additional information or a copy of the catalog: (800) 333-6867 or email: Books@specialneeds.com.


Australia’s First Deafblindness Winter School
Dr Mike Steer
Senior Lecturer, Vision Impairment
Royal Institute for Deaf & Blind Children

In July 1998, Renwick College, the research and teaching arm of the Royal Institute for Deaf and Blind Children, located in Sydney’s northern suburbs, offered Australia’s first postgraduate program to professionals working in the deafblindness field. (Deaf-Blind Perspectives readers will probably be aware that in the Southern hemisphere the seasons are reversed, so that June, July and August are Australia’s winter months.) This “Winter School,” with the title Developing Communication Skills in Students with Sensory Disabilities, was created after a need for more training and development programs for those serving deafblind people in Australia was identified by a 1996 survey commissioned by the National Federation of Blind Citizens of Australia (now called Blind Citizens Australia). Professionals already working in the field and those wishing to work in the field were invited to attend either for postgraduate university credit or as a professional development/continuing education program without university credit.

Among the week’s offerings were sessions on the following topics:
- Critical considerations in developing communication with students who are deafblind
- Defining social interaction as the basis of communication
- Practical steps in developing communication
- Communication and behaviour
- Communication and movement
- Communication in the early years
- Communication that supports inclusive education
- Evaluating and assessing communication program effectiveness
- Assistive technology
- Interpreter skills

The Winter School was widely deemed a remarkable success, given the size of our population (17 million) and the relatively small number of deafblind Australians. A total of 45 people from every Australian state and territory gave up their school vacations or took leave from their positions to attend. Evaluations completed by participants were among the best the college has received for any of its offerings. It was generally thought that the event had given a significant boost to the field of deafblindness nationally.

Keynote lecturers included Dr. Deborah Chen, Professor of Special Education at California State University, Northridge, and Sharon Barrey Grassick, Senior Training Officer with the Western Australian Deaf Blind Association. The five-day program also featured sessions from Kirralee Lewis, Senior Training Officer with the Victorian Deafblind Association; Per Lundgren, from the Guide Dogs Association of NSW; Michelle Burdis, Rob Last, and Christine Muir from the Royal Institute; Dr Angela Wilson, Senior Research Officer of Forsight Foundation, an Australian community agency which focuses on meeting the residential needs of deafblind adults; and Trish James and Irene McMinn from Royal Blind Society and NSW Deafblind Association, both of whom are committee members of the Australian Deafblindness Council, our major national advocacy body.

Organization of an event of this type in a nation that is geographically as large as the continental United States was no mean feat. A great many people made its success possible: the institute staff who provided braille, large print and, in some instances, adaptive technology for participants, the skilled interpreters who ended each day exhausted, the institute’s kitchen staff and particularly its Continuing Education staff and Research Librarian as well as Dr Greg Leigh, Head of Renwick College, who underwrote what turned out to be a relatively costly event that might, for one reason or another, have been poorly attended and result in a financial disaster for the college.

In July 1999, Renwick College plans to offer its second week-long Deafblindness Winter School, this time with a focus on Curriculum for students who are deafblind. The Asian economic crisis, with its impact on Australian currency, currently place our dollar at US $.59, making attendance at this event an attractive proposition to postgraduate students and other interested professionals from overseas. Added to this, Australia, with its unique scenery, flora and fauna, beautiful beaches and wide-open spaces make our country an ideal holiday destination. Further information on the July 1999 Winter School is available from:

Christine Grimmer
Coordinator of Continuing Education
Renwick College
Private Bag 29
Parramatta NSW Australia 2124
rccrg@cc.newcastle.edu.au
Meet the DB-LINK Staff

DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind was formed in October 1992. Since that time, the project has developed into a comprehensive information center with a large collection of materials on deaf-blindness, an extensive web site, and numerous publications. DB-LINK staff members bring a variety of backgrounds to the project, a unique blend of expertise that enhances our services. DB-LINK is a consortium of three primary organizations. Resources and staff are located at each organization: Teaching Research at Western Oregon University in Monmouth, Oregon; Perkins School for the Blind in Watertown, Massachusetts; and Helen Keller National Center in Sands Point, New York.

John Reiman, Ph.D., the Director of DB-LINK, is located at Teaching Research. Since living with a deaf/deaf-blind couple and earning his Comprehensive Skills Certificate (RID) during the mid 1970’s, John has continued both personal and professional relationships with deaf/deaf-blind people. His professional experience in deafness includes directing degree programs at both Gallaudet and Western Oregon University and, since 1990, conducting multiple federal research projects. In 1992, he directed the National Symposium on Deaf-Blindness as well as DB-LINK. He also works as a professional mediator in many contexts.

Gail Leslie, also at Teaching Research is the Project Coordinator and an Information Specialist. She has been with the project since it was initially funded. Gail has a master’s degree in library and information science and prior to coming to DB-LINK worked for 10 years as a public librarian.

The information specialists at Perkins School for the Blind each have master’s degrees in Education and bring significant content experience in deafblindness to the project. Betsy McGinnity has been with the project since it began. She came to DB-LINK with a background in employment and transition issues for youth who are deaf-blind. She has done work nationally and internationally through the Hilton/Perkins Project. Steve Davies has worked in the field of deaf-blindness in many capacities including classroom teacher, itinerant teacher, transition planning specialist, and parent educator. Lisa Jacobs joined the project in September, 1998 and was previously coordinator of the New England Center for Deaf-Blind Services, multi-state 307.11 project. She brings to DB-LINK extensive experience working with children who are deaf-blind, their families, and school personnel.

The two remaining information specialists each have master’s degrees in library and information science. Lois O’Neil, at the Helen Keller National Center, has been a librarian for 10 years. Her previous experience includes work as a medical librarian and as a coordinator of Project Access at New York Public library, a program which provides access to library services for patrons who are disabled. Peggy Malloy, at Teaching Research, is also a librarian and has worked as a medical librarian and writer. She was also a registered nurse for 10 years, working primarily in pediatrics and neonatal intensive care.

Harvey Mar, Ph.D., has been a DB-LINK staff member since early 1994. He serves as a DB-LINK consultant. Harvey is a psychologist in Pediatrics at St.Luke’s-Roosevelt Hospital Center. He has been involved in several special projects pertaining to children and adolescents who are deaf-blind and have other severe disabilities.

Also at Teaching Research are several indispensable support staff. Randy Klumph, who joined DB-LINK in 1992 as our technical specialist, has a bachelor’s degree in psychology. He brings a unique combination of skills to the project including social service experience, desktop publishing, technical illustration, and computer hardware/software technical support. Betsy Martin-Richardson also has a bachelor’s degree in psychology and is the project’s research assistant. She manages most of the office mayhem, including all of the ordering, the organization and distribution of materials, and also maintains our statistics database. Sue Goodson, is a part-time cataloger, who helps develop and maintain our catalog and resource databases. She is currently studying for a master’s degree in information resources and library science.
Deaf-Blind Perspectives is looking for a few good writers!

You put it on paper—we’ll take care of reviewing, editing, and possibly publishing it. Write, email, fax, or tape what you have to say—we’ll take it from there (we might ask you to clarify or revise a bit). The language can be formal, fancy, formidable, funny, forceful, or frisky. The ideas don’t need to be complex, compound, classy, or contorted—though we would like them to be chewy and clear.

What’s in it for you?

- Express yourself
- Share information
- Enjoy a moment of glory
- Contribute to people’s thinking

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503.838.8598 (V/TTY) 503.838.9623 (TTY message)
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Interpreting and Other Issues in the Deaf-Blind Community

Bettendorf, Iowa
June 11-12, 1999

This conference will provide training and information for interpreters, educators, and members of the Deaf and Deaf-Blind communities.

For more information, contact:
Regional Interpreter Training Project/Gallaudet University
Regional Center at Johnson County Community College
(913) 469-3872 v/tty
(913) 469-4416 fax
gurjccc@gallua.gallaudet.edu
http://www.jccc.net/~jaech/
This conference is for families, friends, and professionals. Childcare will be provided for all children. Interpreters and nurses will be available as needed.

Registration forms will be sent to all members of CHARGE Syndrome Foundation, Inc., in late February 1999. You are urged to register early so that plans can be made for childcare, meeting room space, etc.

For more detailed information on hotel rates, registration fees, meals, etc., contact:

CHARGE Syndrome Foundation, Inc.
2004 Parkade Blvd
Columbia, MO 65202
(800) 442-7604 (families)
573-499-4694 (professionals)
Marion@chargesyndrome.org

Do You Need Information and/or Referrals Regarding Children and Youth Who Are Deaf-Blind?

Contact DB-LINK
(800) 438-9376 Voice
(800) 854-7013 TTY
dblink@tr.wou.edu
http://www.tr.wou.edu/dblink

DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind is a federally funded information and referral service that collects, develops and distributes information to help improve the education and lives of children and youth who are deaf-blind.

Services include:

- Information Center
  » Information specialists are available to respond to individual requests for information, including in-depth research.
- Referrals to other organizations
- Web site
- Short topical publications (some available in Spanish)
Active Learning for Individuals with Multiple Disabilities
Innovative Interventions from Denmark

Special Guest Presenter
Lilli Nielsen, Ph.D.
Anchorage, Alaska
August 9–11, 1999

Motivating and meeting the learning needs of children with blindness, deafblindness, and/or multiple disabilities can be challenging. Join Dr. Lilli Nielsen, the originator of “Active Learning” as she provides a fresh innovative approach for creating an active learning environment. Develop and sharpen your skills as an observer, teacher, and role model. Learn how to promote independence in children of all developmental ages, while exchanging perspectives across professions. This conference will also feature demonstrations with children who have multiple disabilities.

Intended audience
Teachers, specialists, therapists, diagnosticians, paraprofessionals, and parents involved with children who have significant multiple needs, including visually impaired and dual-sensory impaired (deafblind) are encouraged to attend.

For more information contact:
Special Education Service Agency
2217 E. Tudor Road, Suite 1
Anchorage, AK 99507
907-562-7372
907-563-8284 TTY
lilli@sesa.org

12th Deafblind International (DbI)
World Conference
Estoril, Portugal
July 20–25, 1999

The theme of this conference is “Developing Through Relationships: Celebrating Achievement.” The conference will be held at the Centro Escolar Turistico e Hoteleiro, in Estoril, an old tourist resort near Lisbon.

For more information, contact:
Casa Pia de Lisboa/CAACF
Av. Do Restelo, 1 1400
Lisboa, Portugal
Ph: 351..1. 362 71 35
Fax: 351..1. 363 34 48
cpl.educa@mail.telepac.pt
http://www.arrakis.es/~apascide/axxiidbi.htm

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Mark appropriate categories (3 max.)

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☐ Special education (e.g., teacher, aide)
☐ Administration (e.g., Dept. of Ed., project director)
☐ Service provider (e.g., social worker, group home)
☐ Technical assistance provider
☐ Higher education teacher/researcher
☐ Regular education (non Spec.-Ed.)
☐ Therapist (e.g., OT/PT/speech)
☐ Teacher trainer
☐ Government personnel
☐ Medical professional
☐ Other ______________________________

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345 N. Monmouth Ave. Monmouth, OR 97361
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All issues of *Deaf-Blind Perspectives* are available on the Internet at [www.tr.wou.edu/trlhb](http://www.tr.wou.edu/trlhb)

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