Supporting Families: Training Family Support Specialists

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A family’s world often turns upside down on the day their child is diagnosed with deaf-blindness. One mother likened the experience to riding the “Scrambler” at a carnival. Just like the physical gyrations of the ride, her mind spun round and round in dizzying circles as she was emotionally pitched from side to side. When she reached a stable center for a fleeting moment, she was immediately flung so far in the opposite direction that she feared she would let loose and fly off into space. The spinning did eventually stop, and she regained her equilibrium. She credits her family, friends, and the state deaf-blind project family specialist with helping her to steady herself and take her first steps in this new life.

Over the past thirty years, the support movement for families of children with disabilities has developed at a rapid pace. Monumental efforts by parents have been the primary impetus. In the early 1970s the first parent-to-parent groups were established, and in the mid-1970s the federal government funded the first parent information centers (Parent Information Center, 2002). In 1994 and again in 2000 Congress enacted the Families of Children with Disabilities Support Act. The first finding in the act states, “It is in the best interest of our Nation to preserve, strengthen, and maintain the family” (Public Law 106-402).

Families are the most likely constant presence in the life of a child with a disability. As a child grows older, the concerns and needs of the family often multiply, creating an ever-growing need for support of the entire family. When the child is an infant, the primary concerns may be related to medical or financial issues. By the time the child is a young adult, the family must consider these, as well as issues related to employment, living arrangements, education, technology, self-advocacy, and conservatorship. An 18-year study of early intervention programs found that if we expect to have an impact on the lives of children, we must offer comprehensive supports for families (Reynolds, Temple, Robertson, & Mann, 2001). The needs of a child are inextricably tied to the needs of the family.

In response to this increased focus on family support, the United States has seen an upward trend toward hiring parent, family, or consumer representatives to assist in designing and delivering support services for specific populations of individuals with disabilities. Indeed, many funding sources now require this representation. There are multiple benefits to this, a few of which are:

- Families often trust one another more than they trust a system.
- Families are driven by personal experiences and passions.
- Families serve as a reality check for programs, ensuring that services are planned and delivered in a way that is effective for families and children.
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Families can clarify the difference between what professionals perceive as needs and what families know are real needs. Diverse families can bring new and different perspectives to the table. (CEPR, 2002)

In recent years, paralleling the national movement, there has been a growth in family support services among the state and multistate deaf-blind projects. This growth is evidenced by the vast array of family activities provided by the state projects and the increased number of projects that employ a family specialist or consultant to assist in developing and implementing family support services.

Over the past seven years, NTAC (National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind), in collaboration with the Hilton/Perkins Program, has had the opportunity to support this movement through a multi-year training program for the family specialists and consultants working with deaf-blind projects. A family specialist or consultant is an individual who has considerable involvement, paid or volunteer, in the planning, implementation, and evaluation of the state deaf-blind project’s technical assistance, training, and support to families of children who are deaf-blind. Most of these individuals are family members who understand and can empathize with the concerns and needs of other families. However, they may or may not have the skills needed to deliver technical assistance and training. To address this need for skills training, NTAC and Hilton/Perkins offered the first workshop for family specialists in October 1998. Fifteen of approximately twenty family specialists working with deaf-blind projects attended the training. Since that time, four additional workshops have been held, most recently in June 2003 at the Helen Keller National Center in Sands Point, New York. Family specialists representing 17 state projects attended. Currently, 26 state deaf-blind projects employ one or more family specialists or consultants.

The primary goal of each workshop has been to build the confidence and skills of the family specialists so that they can effectively provide support to families in their states. The workshops have covered a variety of subjects including:

- family dynamics and relationships
- personality, self-awareness, and the effect one may have on others
- effective communication and conflict resolution
- learning styles and effective training strategies
- leadership and team building
- balancing physical and emotional health as caregivers
- social/sexual relationships and deaf-blindness
- self-determination within family structures
- technical assistance strategies for families
Formal and informal evaluation of the training activities has consistently demonstrated their value. During the spring of 2003 a follow-up survey was completed by family specialists who had participated in at least one of the trainings over the past five years. Their comments revealed that the training not only had a positive effect on the participants personally, but also improved their ability to work more effectively with families, service providers, and agencies in their states:

The training gave me the opportunity to look at myself and understand that my reactions and personality set the tone of how I am going to treat and work with my family as well as other families.

Understanding my own self (personality, family of origin, learning style, etc.) has helped me relate better to my son. I am a MUCH more effective parent and advocate for my son.

I have learned how to communicate with families better. I no longer overwhelm families with information and assistance. I have learned to provide what I am asked for when it is needed. This has made my relationship with the families in my state so much more relaxed, and in turn they feel more comfortable asking me to do more.

The contact that I made during these trainings has led to collaborations resulting in a number of articles for our newsletter... Many families and professionals have requested copies of these and other articles resulting from contacts made or information received at these meetings.

I now have more skills in working with service providers on both specific topics and also [on giving] them the perspective of the parents, in a way that is honest, but in terms that they understand. It also gives credence to things the families may have told them that they previously dismissed as being too emotional.

If I can be more effective in my personal relationships with professionals we form a stronger alliance and bond of mutual trust. This does help improve services. I have seen services change because if teams trust me/my team they are much more willing to implement the suggestions we make.

The project that I work on now provides technical assistance that is directed much more to the individual family and circumstance and less of a generic nature.

There are several factors that contribute to the positive results of this ongoing training program. In the literature on family support, the concepts of relationships, consistency, and adequate, flexible support are mentioned repeatedly as aspects of an effective family support system. All of these factors are built into the family specialist training program.

A relationship of respect and trust was thoughtfully developed in the first few years of training and has been fostered in each workshop since. With the assistance of two experienced consultants, Marilyn Minkin and Cathy Kirscher, the family specialists have participated in activities and discussions that have prompted them to explore personal aspects of their own lives and their roles in their own families. The purpose was to gain an understanding of and empathy for the experiences of other families. This activity built a foundation of trust that was obvious in each workshop as demonstrated by the frequency and depth of the group discussions.

Twelve family specialists have attended at least three of the five workshops. Several more have attended at least two. This consistency enhances the skills of the participants as new knowledge and skills are layered upon previous learning. Many of the family specialists have become highly competent and skilled and are tremendous mentors for less experienced family specialists.

The Hilton/Perkins Program, NTAC, and the state deaf-blind projects have demonstrated their commitment to the family specialists by providing financial support for the training initiative. Each of these entities also provides ongoing informal support to the family specialists throughout the year. The parameters guiding the use of the financial support have been flexible enough to allow the planning team to meet identified needs in the manner that it feels will be most effective. This flexibility has resulted in workshop programs that are very exciting, experiential, and sometimes nontraditional. Although a portion of the agenda may be lecture, the majority of time is spent engaged in activities designed to demonstrate and practice new skills.

Professionals cannot fully understand the strengths, needs, and educational requirements of a child who is deaf-blind without understanding the influence of the family on the child’s life. Family specialists are the key to this understanding because they have the ability to reach a family like no other professional can. It is natural to connect more readily with someone who shares your life experiences. However, in order to have a sustaining impact on a family and child, the family specialist may need additional skills. Ongoing training and support is essential to improve and maintain the effectiveness of the family support activities of state and multistate deaf-blind projects.
References


Siblings: Unusual Concerns … Unusual Opportunities

Julie and Mark Martindale

It was a Sunday morning, and we were frantically rounding up our four young children at church, when a few words from an acquaintance stopped us in our tracks. It was Christmas time, and all the children were supposed to sing in the school program that evening. Our son, who uses a wheelchair and is DeafBlind, was going to be part of the program with all the other children. As this person looked down at Aaron sitting in his chair, she asked, “Is he going to be in the program? He can’t sing.” Many emotions stirred in us immediately—anger and hurt at the insensitivity of this individual and even embarrassment and self-doubt. Maybe we should not have put him in the musical.

It was our son Tyler who answered the woman simply and eloquently as we stood there still stumbling for the words to say. Tyler said with confidence and pride, “My brother can sing. He sings with his eyes.”

If some day you meet our son Aaron, you will know what Tyler is talking about—because Aaron does sing with his eyes and he says more with one smile than most of us can say with a thousand words.

But it was Tyler who amazed us the most with his answer. It reflected acceptance, insight, and maturity beyond his years. This was a turning point for us. We know that in all the worrying we had done over our typically developing children, we had lost sight of the benefits that come from having a sibling with special needs. It is not an easy road for siblings, but along the way they learn skills and form attitudes that can help them throughout life. Their experiences are not really that different from ours as parents. They didn’t choose this road for themselves, and through the tough times they learn that life is not to be taken for granted. And with our help, they can emerge as stronger, more sensitive, and self-assured human beings, just like us as parents.

We’ve spent a lot of time worrying about the effects of the extra attention that our special needs children get. How could we possibly explain to a two year old why the physical therapist was coming to play with his baby sister, but not with him? She is “special,” but so is he. Was this going to make him feel insecure? Would he feel too much pressure to be the one to succeed because his siblings wouldn’t be able to do all that he was able to accomplish? Would he grow up resentful or angry?

In the book by Donald J. Meyer et al., Sibshops: Workshops for Siblings of Children with Special Needs (Paul H. Brookes Publishing Co., 1994), the authors list some of the most common concerns that are associated with being a sibling of a child with special needs and also some of the many positive opportunities for growth that siblings have. Here are some examples:

<table>
<thead>
<tr>
<th>Unusual Concerns</th>
<th>Unusual Opportunities</th>
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<tbody>
<tr>
<td>overidentification</td>
<td>maturity</td>
</tr>
<tr>
<td>embarrassment</td>
<td>self-concept &amp; social competence</td>
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<tr>
<td>guilt</td>
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<tr>
<td>isolation or loss</td>
<td>loyalty</td>
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<tr>
<td>resentment</td>
<td>vocational opportunities</td>
</tr>
<tr>
<td>increased responsibility</td>
<td>pride</td>
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<td>pressure to achieve</td>
<td>advocacy skills</td>
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</tbody>
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In spite of the difficulties, there are great joys. The siblings see all of it, sometimes more than we do. We have a lot to learn from our typical kids and we are learning to listen to them more and more. We have decided not to worry so much (OK, we know it is easier said than done) about the negative possibilities that can affect our kids. We’re learning to worry less and experience life more. As we seek to enjoy the little things in life and to learn from the difficult times that come our way, just maybe our attitude will shape the attitudes of our children. But most likely, it will be our children teaching us.

The Martindales live in Anoka Minnesota.

Guest Editorial

Spotlight on Assistive Technology

Jon Harding
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In order to successfully educate children who are deafblind, educators must use the best educational practices available. Assistive technology (AT) is one component of an educational program that can help deafblind children reach their full potential. A number of factors, however, often limit the use of these tools, including a lack of research data, unclear legal requirements, and limited knowledge about the benefits that AT can provide. Because of this, deafblind children are often denied the opportunity to access technology that could help them communicate, participate, socialize, and explore. All of these obstacles can be overcome, however, when all people involved in the lives of children who are deafblind are committed to the expansion of the use of assistive technology.

Children identified as deafblind have vision and hearing losses that impact learning, mobility, communication, and social and behavioral skills. In addition, cognitive or physical disabilities and medical problems are often present, creating challenges that can be overwhelming for teachers, therapists, counselors, and aides. It is unthinkable that these children with the most significant learning obstacles not be given close scrutiny to determine if AT might be necessary to meet their educational goals.

The Individuals with Disabilities Education Act (IDEA) is a federal law that requires that all children with an IEP (individualized education program) must be considered for assistive technology. The law recognizes the value of AT and is designed to ensure that children with special needs have access to AT if it is needed to meet their educational goals. It seems logical to assume that children with the most significant obstacles to learning, including deafblind children, would be given thorough consideration. There is no literature to suggest, however, that all (or even a majority of) deafblind children are fortunate enough to be considered for AT on more than a cursory basis.

During IEP development, teachers are required to consider and document an array of factors related to a student’s educational program. These include (but are not limited to) the student’s present level of performance, learning characteristics, social and physical development, near-term goals, desired post-school outcomes, special and related services, transportation, and accommodations. Considering the litany of factors to consider, it’s easy to see how AT might be overlooked.

It is important to note a couple of points. First, the ultimate goal for educators is not to acquire a device for a particular child, but rather to explore which devices and services are appropriate to allow participation and to meet educational goals. Second, increasing the awareness of AT should not lessen, but rather complement the value of other interventions and therapies such as the use of intervenors, vision assessments, and person-centered planning. Finally, AT should assume a prominent place in professional discussion about promising practices. The reality is that when AT is overlooked as a service, the negative consequences are the greatest for deafblind children.

Listed below are some of the obstacles that inhibit the acquisition and use of AT and suggested actions to overcome the obstacles. While these problems are

Definitions

IDEA defines an assistive technology device as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability.”

An assistive technology service “means any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device.”
complicated and the responses simplistic, it is an attempt to further a dialogue about assistive technology and deafblindness.

1. There is a lack of reliable data about AT and its use with deafblind children.

Very little data is available about the use and effectiveness of assistive technology for students who are deafblind. If there were data suggesting that, in general, AT is not being used with deafblind children, then we would need to ask why and take action to correct the situation.

Response: There is an obvious need to gather qualitative and quantitative data on the consideration process for and the acquisition, use, and effectiveness of AT for deafblind students so that the field can make decisions about how to best ensure that all of these children are considered consistently and fairly. As an initial step, state deafblind projects should be encouraged to collect and share data on the use of AT by students in their census. It is feasible to determine how many students are using AT, what kind is being used, and whether it is included on the IEP. The resulting data could help clarify a response.

2. Deafblind advocacy groups have not made assistive technology for deafblind students a priority.

Assistive technology has not received the same focus of attention by the deafblind community as other issues have. Etiology, identification, transition, inclusion, and evaluation are often explored and debated, but AT remains an ancillary topic. Despite the fact that communication development is strongly emphasized (and rightly so), there has not been enough attention given to the augmentation of communication via technology.

Response: Family and professional advocacy groups, both state and federal, should work to promote the use of assistive technology to achieve educational goals. State deafblind project personnel should include individuals knowledgeable about assistive technology resources in their states and should encourage schools to consider AT for deafblind children.

3. Existing best practices in the field of AT are not being implemented or effectively promoted for deafblind children.

Existing professional standards and practice recommendations are available to help implement assistive technology services for children with all types of disabilities. There is no need for duplicate forms or guidelines for children with deafblindness.


4. The AT provisions in IDEA are not enforced.

IDEA states that IEP teams must consider whether a child requires assistive technology devices and services but does not define the term “consider.” If an IEP team decides that no AT is required for a particular student, the decision is typically not justified or explained.

Response: Advocacy groups should lobby federal legislators to amend the AT provisions within IDEA to define the phrase “must be considered.” IEPs must explain how a student was considered for AT and why AT was not required if that was the determination. State compliance boards should be encouraged to emphasize the importance of AT as a component of the IEP.

5. Parents of children who are deafblind have not made AT a priority when advocating for services.

Historically, the impetus for meaningful change in policy and practice in the field of disabilities has come from parents who have organized to testify and lobby on behalf of their children.

Response: Parents of children who are deafblind could connect with other disability groups to advocate and lobby to ensure that deafblind children receive AT consideration and benefits. Existing deafblind parent support groups could create position papers, call local legislators, and connect with local parent training and information centers to promote AT awareness in their communities.

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Computer Activities to Support Communication and Language Development in Children Who Are Deafblind

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Beginning during preschool and continuing throughout the school years, computer activities may be used to promote language acquisition and communication development in children who are deafblind. They may be used to support children’s communicative behaviors and interactions; to improve their understanding of symbols, pictures, and words; and to promote the development of formal written language.

A child’s physical, sensory, and cognitive abilities are important considerations for the design of computer activities. Computer input and output methods should be based on an assessment of a child’s physical and sensory abilities. The type and content of activities should generally be determined by a child’s cognitive abilities as well as by the educational objectives. An assistive technology evaluation to determine specific technology solutions for an individual child should be performed by someone who is both familiar with the unique needs of deafblind children and knowledgeable about current technology.

Teaching suggestions and examples of successful computer activities used with children in the Deafblind Program at Perkins School for the Blind will be shared here. Many other software programs and hardware solutions are also appropriate for children who are deafblind, and new technologies are continually being developed. A single software program can address multiple areas of the curriculum and can benefit children of different ages and abilities depending on how it is used with an individual child. Some programs are designed specifically to support one type of activity such as cause and effect or picture matching. Others are limited only by the creativity of the individual designing the activity.

Computer Activities

Effective computer activities designed to support communication include:

- the teaching of cause-and-effect relationships
- early language development activities such as symbol recognition, choice making, requesting, and labeling
- continued language development and expansion

Children who have some usable vision can benefit by participating in these activities. Those who are totally deafblind can be introduced to the computer only after acquiring enough language and knowledge of braille to successfully operate a refreshable braille display for computer access.

Teaching Cause and Effect Relationships

Children who demonstrate an ability to visually attend for short periods of time can be introduced to the computer for activities that teach the concept of cause and effect. It is important that the selected software program draws the child’s visual attention immediately to the screen and provides direct feedback for his or her actions. A monitor with a built-in touch screen makes it possible for a child to establish a direct link between an action and the resulting activity that appears on the screen. The child should be seated in front of the monitor in an optimal position for viewing the screen at eye level. An adjustable chair or table should be used if necessary. Extraneous equipment, such as the keyboard and mouse, should be moved out of reach. High-quality amplified computer speakers can be used to provide auditory feedback that enhances the experience.

A teacher introduces the activity by first modeling the action of touching the screen, then by providing hand-under-hand assistance to the child if necessary. Children learn that they can produce an effect by touching the screen because they receive immediate reinforcement in the form of a change in a pattern, sound, or animation. Once a child has demonstrated an understanding of the relationship between cause and effect using a touch screen, an indirect access tool is introduced. This is usually in the form of a switch or mouse button. However, some children need to take smaller steps away from direct touch by first using a handheld tool such as a stylus or a pointer made from thermoplastic material.

Software programs that utilize a single switch or mouse click and present instant feedback in the form of bold colored patterns displayed on a solid or uncluttered background and accompanied by distinct sounds are preferred. Ideally, programs should present images and information in a consistent and predictable location. The possibility of a child’s missing the visual reward is reduced if he or she can anticipate the appearance of a particular graphic or animation in a specific location on the
screen. As children learn where to look for an action, they can have more meaningful and successful interactions with the computer.

An example of a program that can be used for cause-and-effect activities is SwitchIt! Suite (IntelliTools). This suite provides options for changing images, colors, and the number of switch activations needed before an animated reward is presented, and it consists of four separate programs with display options ranging from simple patterns with large, bold components to complex fine-line drawings. The complexity and number of graphics presented on the screen at one time can gradually be increased as a child demonstrates understanding of an activity and the ability to visually discriminate the content. Other programs are Creature Antics (Laureate), which presents slightly more complex animated creature characters against a solid black background, and Eensy and Friends (Don Johnston), which has large, colorful graphics and stable background images, for use when a child is ready to process an increased number of visual variables as part of an activity.

**Early Language Development Activities**

Successful early computer experiences build a foundation for more complex interactions as activities transition from random cause-and-effect exercises to early language development activities such as symbol recognition, matching, choice making, requesting, and labeling.

*Symbol recognition.* One activity to help children learn how to use symbols for communication involves matching images of symbols displayed on a computer screen to the same symbols displayed on a card. Using a screen-capture utility, screen images can be duplicated, printed on cards, and laminated. Then, as an image appears on the screen, a teacher presents a card with the matching image to the child. A strip of Velcro placed on the front of the monitor allows the symbol to be placed next to the screen, leaving the teacher’s hands free for signing. Over time, as a child’s recognition of symbols increases, several cards are presented at one time and the child is encouraged to choose favorite programs or patterns. These types of interactions promote the use of language as the child makes requests or indicates preferences and the teacher responds immediately with a combination of signs, symbols, and the requested computer animations.

*Labeling and matching.* Once a child can demonstrate an ability to discriminate and recognize pictures (photographs, line drawings, or graphical symbols), computer activities can be expanded to include labeling and matching. Many educational software programs used for this purpose have appropriate content but are inaccessible to children with severe visual impairments. However, some programs allow easy customization of lessons by combining sounds, picture communication symbols, computer graphics, digital images, movies, and text in a format that is appropriate for each child. Meaningful language-based activities can be created with multimedia authoring programs found in many elementary schools such as HyperStudio (Sunburst) or IntelliPics Studio (IntelliTools).

The program Stickybear Opposites Deluxe (Optimum Resource, Inc.) uses clear bold animated graphics to illustrate basic concepts such as on/off, up/down, in/out, and big/small, and provides multiple opportunities to support language development by talking or signing about the animation as it plays out on the screen. Words Around Me (Riverdeep/Edmark) focuses on developing common vocabulary by using photographs and drawings for lessons in labeling, matching, and categorizing. The teacher facilitates interaction with the program by signing as the pictures are identified and labeled and as directions for matching are given in digitized speech.

Customized computer activities for picture matching utilize images representing the features of a child’s daily routine or photographs of family members and classmates. Initially, the child is asked to find two similar images on the screen and “drag” them together make a match. At a higher level, the child is required to look away from the screen and locate the match on an alternative keyboard such as the IntelliKeys keyboard (IntelliTools). OverlayMaker (IntelliTools) can be used to create keyboard overlays appropriate for a child’s visual and cognitive abilities.

**Continued Language Development and Expansion**

As a child’s language abilities develop, computer activities can be used for storytelling and to teach reading and writing. Initially, programs are used that encourage the child to use pictures and photographs for communication and self-expression.

Children who recognize and understand photographs particularly enjoy computer activities that integrate photographs of themselves and their classmates. With IntelliPics Studio, a teacher and child work together to create experience stories about field trips, special events, and classroom activities. They illustrate events using a picture of the child, classmates, and other aspects of an experience that appear on palettes as clip art choices and backgrounds within the program. The child and teacher
discuss the event through the selection and placement of these images. Through manipulation of his own image, the child expresses himself even when he does not have the specific vocabulary to do so. The teacher takes advantage of this opportunity to teach formal language by using signs, speech, or written words that describe the child’s actions. He or she provides additional language instruction by using overlays on the IntelliKeys keyboard. The child selects keys containing words or phrases on the overlay to label pictures or create simple sentences.

Children can write sentences with picture support using a program such as Clicker 4 (Crick Software), a word processor that integrates the Mayer-Johnson Picture Communication Symbols with text. On-screen grids containing pictures and words based on a child’s particular language abilities facilitate sentence formation. A teacher discusses an event with the child by asking questions and encouraging written self-expression by the selection of words and symbols from the grids. The document is printed and added to a notebook that serves as a journal of the child’s experiences for later review, further discussion, or sharing with others.

As written language develops, the child types words on a keyboard and the use of symbols and grids is decreased. An IntelliKeys keyboard is used with a large-print alphabet in a QWERTY layout to facilitate eventual transition to a standard computer keyboard. Initially, the child uses the on-screen grids as a model for word choices or sentence structure and merely copies the text. Later, the child is challenged to recall spelling words from memory or type them with fingerspelling help from the teacher. The child is motivated to write experience stories, letters to others, and lists for shopping or cooking. The teacher encourages writing development by providing assistance with vocabulary and language.

The interaction between children and teachers during computer time is very valuable for language acquisition and development. There is a careful balance between teaching a child to use the computer and teaching a child language using a computer. When that balance is achieved, the computer can be a very powerful tool for learning and using language.

### Hardware and Software Modifications

The keyboard and mouse generally provide the primary computer input. These devices can serve as barriers for many deafblind children because of visual or physical limitations, but simple adaptations are possible. Children may need to have a particular set of skills before some of these adaptations can be used. In some instances, these skills can be taught as the adaptation is introduced. In other cases, a foundation must be in place before the skills that the adaptation requires can be taught. Introduction of complex devices before a child demonstrates understanding of specific concepts or has the required motor skills can result in unnecessary failure and even rejection of the technology. The development of important foundations supports a child’s readiness for the use of more sophisticated technologies and ultimately determines their effectiveness.

#### Simple modifications for the mouse:

- Place the mouse on a box to bring it closer to the screen.
- Place the mouse on a slanted surface to reinforce the concepts of up and down.
- Use a tactile “reminder” such as a small dot of fuzzy Velcro on the mouse button.
- Adjust the tracking speed in the mouse control panel.
- Modify the size or color of the pointer through the mouse control panel (Windows only).
- Use a double-sized mouse pad to increase the “mousing” area.
- Use a solid-colored mouse pad for contrast.
- Use a one-button mouse (Apple).
- Control the left and right mouse button functions through the control panel (Windows only).

#### Specialized hardware as a replacement for the mouse:

- built-in or external touch screen
- joystick
- trackball
- trackpad
- head mouse
- switch interface with single switches

#### Add-on software modifications for the mouse or mouse replacement:

- modified or enlarged pointer/cursor
- “hot spot” control panel
software assistance for clicking and dragging

**Simple modifications for the keyboard:**
- Place large-print stickers directly on the keyboard or on a moisture guard that is placed on the keyboard.
- Place the keyboard on a slanted surface.
- Use a keyguard to prevent unwanted activations.
- Cover unused keys to reduce distractions.
- Turn on “sticky keys” in the keyboard control panel.
- Slow the repeat rate or ignore repeated keystrokes in the keyboard control panel.

**Specialized hardware as a replacement for the standard keyboard:**
- expanded or membrane keyboard
- switch interface
- “biggy” keyboard with enlarged keys
- refreshable braille display
- braille notetaker (to be used instead of a computer)

**Add-on software modifications for the keyboard:**
- simple on-screen software keyboard
- software to customize overlays for an alternative keyboard
- scanning software with a switch interface

Visual output is a major component of most computer activities for children. Software programs contain colorful graphics and animation, with integrated sounds, digitized speech, or music. Inability to see graphics or hear sounds may limit but does not always have to prevent a child’s use of a software program.

**Simple modifications for the screen:**
- Place the monitor directly on a table or on a box to adjust the height for optimal viewing.
- Reduce glare from light sources in the room by thoughtful placement of the computer in relation to windows and overhead lighting.
- Reduce glare by attaching a “hood” to the monitor to block light sources from the sides and top.

- Adjust the size of fonts, icons, and the pointer through control panels.
- Reduce screen resolution to increase viewing size.
- Use an adjustable chair or table.

**Specialized modifications for the screen:**
- Consider the size of the monitor and the child’s visual field. A larger or smaller screen size may be appropriate.
- Place the monitor on an adjustable arm for quick repositioning.
- Use screen magnification software.
- Use speech output software or speech features built into software programs.
- Use a refreshable braille display.

**Modifications for sound output:**
- headphones
- patch cord between the headphone jack and hearing aid or FM unit
- amplified external computer speakers

**Information Resources**

**Organizations**

**Closing the Gap**
(International organization)
P.O. Box 68
Henderson, MN 56044
507-248-3294
info@closingthegap.com
http://www.closingthegap.com

**ABLEDATA**
(Assistive technology database)
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
800-227-0216
301-608-8912 TTY
abledata@orcmacro.com
http://www.abledata.com

**Assistive Technology Industry Association**
(Organization of manufacturers and providers of assistive technology devices and services)
401 North Michigan Avenue
MC: 2200-1
Chicago, IL 60611-4267
877-OUR-ATIA (877-687-2842)
info@atia.org
http://www.atia.org
Assistive Technology Companies

Ablenet, Inc.
(Switches, switch interfaces)
1081 10th Ave. S.E.
Minneapolis, MN 55414
800-322-0956
customerservice@ablenetinc.com
http://www.ablenetinc.com

Ai Squared
(Screen magnification software)
P.O. Box 669
Manchester Center, VT 05255
800-859-0270
sales@aisquared.com
http://www.aisquared.com

Alva Access Group, Inc.
(Braille displays, notetakers, and screen readers)
436 14th St., Suite 700
Oakland, CA 94612
888-318-2582
info@aagi.com
http://www.aagi.com

Crick Software
(Clicker 4)
50 116th Ave S.E., Suite 211
Bellevue, WA 98004
866-332-7425
info@cricksoft.com
http://www.cricksoft.com

Don Johnston Incorporated
(Switches, switch interfaces, Eensy & Friends, On A Green Bus, A Day at Play)
26799 West Commerce Drive
Volo, IL 60073
800-999-4660
info@donjohnston.com
http://www.donjohnston.com

Riverdeep/Edmark
(Touch Window, Words Around Me, Bailey’s Book House, Millie’s Math House)
500 Redwood Blvd.
Novato, CA 94947
415-763-4700
info@riverdeep.net
http://www.riverdeep.net/edmark

Educational Resources
(KidPix Studio, Stickybear Opposites Deluxe, general educational software and hardware)
1550 Executive Drive
Elgin, IL 60123
800-860-7004
http://www.edresources.com

Freedom Scientific
(Braille notetakers, displays, and embossers; screen magnification software)
11800 31st Court N.
St. Petersburg, FL 33716-1805
800-444-4443
info@FreedomScientific.com
http://www.freedomscientific.com

IntelliTools, Inc.
(IntelliKeys, IntelliPics Studio, Overlay Maker, SwitchIt! Suite)
1720 Corporate Circle
Petaluma, CA 94954
800-899-6687
info@intellitools.com
http://www.intellitools.com

Laureate Learning Systems, Inc.
(Creature Antics, Creature Capers)
110 East Spring Street
Winooski, VT 05404-1898
800-562-6801
customer-service@laureatelearning.com
http://www.laureatelearning.com

Mayer-Johnson Co.
(Mayer-Johnson Picture Communication Symbols)
P.O. Box 1579
Solana Beach, CA 92075
800-588-4548
mayerj@mayer-johnson.com
http://www.mayer-johnson.com

R. J. Cooper & Associates
(Magic Arm switch mount, cause-and-effect software)
27601 Forbes Rd., Suite 39
Laguna Niguel, CA 92677
800-752-6673
info@rjcooper.com
http://www.rjcooper.com

SoftTouch
(Old Mac’s Farm)
4300 Stine Road, Suite 401
Bakersfield, CA 93309
877-763-8868
softtouch@funsoftware.com
http://www.funsoftware.com

Sunburst Technology
(HyperStudio)
1550 Executive Drive
Elgin, IL 60123
800-321-7511
http://www.sunburst.com
Switch In Time
(Free switch accessible software for Macintosh, Scan’n Read, KidBook)
172 Harvard Road
Littleton, MA 01460
978-486-9433
adams@switchintime.com
http://www.switchintime.com

Troll Touch
(Touch screens: add-on and built-in)
25530 Avenue Stanford, Suite 201
Valencia, CA 91355-1131
661-257-1160
info@trolltouch.com
http://www.trolltouch.com

Research Update
Peggy Malloy
Managing Editor

Deaf-Blind Perspectives would like to begin a recurring “Research Update” section consisting of short announcements related to research in deaf-blindness. Researchers and other interested individuals or agencies may use this column to share information about new, ongoing, or recently completed research projects. We are interested in information from both the United States and international sources. Examples of the types of announcements that may be posted include:

• announcements by researchers who are currently doing research in a particular area and would like to know if there are others working on the same topic or just generally would like to let people know about their ongoing work;
• new or recent publications related to research;
• requests for individuals to participate in a research study.

We hope that people will be interested in contributing to this column and that it will serve as a focused place within Deaf-Blind Perspectives where people can look for information about research. If you are interested in contributing an announcement or have questions, contact:

Peggy Malloy
Managing Editor
malloyp@wou.edu

503-838-8598 (V/TTY)
Teaching Research
345 N. Monmouth Ave.
Monmouth, OR 97361

Request for Study Group Participants

The Persons Aging with Hearing & Vision Loss Project is looking for individuals over the age of 55 to participate in a three-to-five-year study exploring ways to improve employment and community integration outcomes for persons who are deaf or blind and who are experiencing a secondary onset of vision or hearing loss as a result of aging. Although the project focuses on individuals who acquired one loss before the age of 55 and the second loss after the age of 55, all persons over 55 with both losses are eligible to participate. Collaborating in this project are the Mississippi State University Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision, the Helen Keller National Center, and the RRTC on Persons Who Are Hard of Hearing or Late Deafened at National University in San Diego.

For more information or for a study group application, contact:

B. J. LeJeune, Principle Investigator
Rehabilitation Research and Training Center on Blindness and Low Vision
Mississippi State University
P.O. Box 6189
Mississippi State, MS 39762
800-675-7782
662-325-8693 TTY
bjlejeune@colled.msstate.edu

New Publication


U.S. Department of Education Research Projects in Deaf-Blindness

On July 28, the U.S. Department of Education Office of Special Education and Rehabilitative Services made available grant applications for research validation and implementation projects for children who are deaf-blind. A maximum of three grants will be awarded in amounts of up to $205,000 per year for periods of up to five years. The application deadline was August 27. An announcement of the grant awards will be made in the Winter 2003/2004 issue of Deaf-Blind Perspectives.
Report on the International CHARGE Syndrome Conference

Betsy McGinnity
Information Specialist
DB-LINK

About 400 people from 32 states and 7 foreign countries attended the 6th International CHARGE Syndrome Conference this summer in Cleveland, Ohio. The majority of participants were family members of a child with CHARGE Syndrome. In addition to a rich and varied schedule of presentations and events, the conference also included a day camp for children with CHARGE and their siblings.

Topical Sessions

The agenda featured sessions that focused on research, medical issues, and education. Presenters included experts from the Netherlands, Australia, Canada, France, Norway, and the United States. Many of the presentations revisited and updated issues that have been addressed at past conferences including research into the genetic causes of CHARGE, endocrinology, puberty, toileting, sleep problems, feeding issues, hearing, vision, and communication. This year, educational issues such as intervenors, curriculum access, teaching strategies, and transition were also strongly emphasized. A few sessions focused on young adults with CHARGE and discussed transition planning and independent living. A highlight of the conference was a panel of adults with CHARGE Syndrome who shared their stories and experiences and answered questions from families in the audience.

Behavior Symposium

Another conference highlight was the Behavior Symposium. Through the efforts of Tim Hartshorne and with financial support from Central Michigan University, NTAC, and the Helen Keller National Center, a specific Behavior Symposium was included for the first time at a CHARGE Syndrome Conference. Researchers, educators, and families gathered to discuss the challenging behaviors exhibited by children with CHARGE Syndrome.

- Jan van Dijk of the Netherlands discussed how sensory deficits affect behavior and described strategies to help children make sense of the world and communicate their needs. He emphasized the importance of establishing a bond with each child, using assistive listening devices and low vision aids, adapting each child’s environment, and establishing predictable routines.
- George Williams from Australia talked about postnatal experience including developmental care and the development of attachment and their influence on self-regulation and behavior.
- Several speakers reported the results of surveys that examined the relationship between such factors as the number of hospitalizations experienced by a child with CHARGE, vestibular problems, social and communication problems, and the incidence of difficult behaviors.
- Jacques Souriau from France discussed survey results indicating correlations between behavior difficulties and left-handedness, insensitivity to pain, and difficulty understanding and using social rules.
- Tim Hartshorne of Central Michigan University discussed his research examining whether the autistic-like behavior of children with CHARGE is more similar to that of children who are deafblind or to that of children who are autistic.
- Laurie Denno of the Perkins School for the Blind Deafblind Program discussed repetitive behaviors. Her research has identified a need to accurately match treatment strategies with the results of a functional behavior analysis.
- David Brown of California Deaf-Blind Services reported on the impact of an absent vestibular system and its relationship to the often unusual behaviors of children with CHARGE.
- Jude Nicholas of Norway discussed the role of central nervous system disturbances as a contributing factor in behavior problems.
- Kim Blake, Canada, and John Graham, United States, discussed research that concluded that typical CHARGE behavioral features appear to be due to sensory impairments affecting hearing, facial nerves, and vision.

All of the presenters agreed that there is a need for further research and collaborative work. Hopefully, the Behavior Symposium will become a regular feature of the CHARGE conference.
Social Activities

There were many opportunities for families to interact with one another. Informal meetings at meals, at the pool, and in the elevator offered a chance for people to connect and compare experiences. Social events included a carnival and silent auction. Although nothing compares with actually attending the conference, the sessions were recorded and most presenters submitted handouts. Both the videotapes and the conference proceedings are available from:

CHARGE Syndrome Foundation, Inc.
2004 Parkade Boulevard
Columbia, MO 65202-3121
800-442-7604 or 573-499-4694
conference@chargesyndrome.org
http://www.chargesyndrome.org/

For Your Library


This is an interactive CD-ROM on the behavior problems that are often associated with CHARGE Syndrome. Four children ranging in age from 15 months to 12 years and who exhibit stereotypical behavior, noncompliance, aggression, or self-injury are discussed. Through the use of video clips, challenging behaviors and the reactions of service providers are demonstrated. By means of questions and answers, the viewer is taken through a process of analyzing behaviors. The analysis leads to recommendations for prevention and intervention. The use of cochlear implants to prevent problem behaviors in some children is also addressed. To order, send a check for $35.00 to Mr. Joe Franken, 4619 Spyglass Drive, Dallas, TX 75287. Indicate “CHARGE” on the check.

Touching Lives: Portraits of Deaf-Blind People (Video, 56:30 minutes) - Gordon, Myles & Hajjar, Susan.

Produced over a four-year period, Touching Lives focuses on the lives, trials, and triumphs of people who are deaf-blind. The goal of the video is to raise awareness about deaf-blindness and to assist deaf-blind people in their struggle to improve the quality of their lives. It is narrated by Susan Hajjar, a hearing-sighted woman with three deaf-blind siblings and a noted advocate for the rights of deaf-blind people and co-founder of Boston’s Deaf-Blind Contact Center. To order send a check for $35.00 made out to The Center for Independent Documentary and mail to: Myles Gordon, c/o Touching Lives, 54 McCarthy Rd., Newton, MA 02459. E-mail: touchinglivesfilm@rcn.com.


American Foundation for the Blind and Art Education for the Blind have joined together to co-publish this resource book that provides information on all aspects of exploring art and creativity by people who are blind or visually impaired. This illustrated manual is the result of a decade-long international collaboration among researchers, art educators, teachers of visually impaired students, psychologists, museum professionals, and blind and sighted art enthusiasts. Includes a section of reproducible pages for classroom or workshop activities. Cost: $69.95. Available from AFB Press. Phone: 800-232-3044. E-mail: afborder@abdintl.com. Web: http://www.afb.org/store.

Conferences

Assistive Technology Expo 2003 December Pennsylvania

Assistive Technology Expos will be held on December 2 (Monroeville), December 3 (State College), and December 4 (King of Prussia). Manufacturers, Intermediate Unit Assistive Technology staff, and Pennsylvania Training and Technical Assistance Network staff (including deafblind project staff) will be available to demonstrate equipment, answer questions, and assist participants in finding solutions to assistive technology needs. Brochure and registration information may be found at ftp://ftp.pattan.k12.pa.us/pattan/Flyers03/Expo03.pdf. There is no fee. Parents of children and youth who are deaf-blind are encouraged to contact Nancy Lehr at 800-360-7282, ext. 3115, if interested in setting up a time to explore the Expo with a staff member of the deafblind project.
Getting in Touch with Literacy Conference
December 4-7, 2003
Vancouver, British Columbia

This conference addresses issues related to literacy for individuals with visual impairments at all age and literacy levels. It is anticipated that presentations will include information on reading and writing in braille, use of assistive technology, use of a variety of literacy tools, and other relevant topics.

Contact:
Cay Holbrook (co-chair)
University of British Columbia
604-822-2235
cay.holbrook@ubc.ca
http://www.gettingintouchwithliteracy.org

CSUN’s 19th Annual International Conference
on Technology and Persons with Disabilities
March 15–20, 2004
Los Angeles

Sponsored by Center on Disabilities, California State University, Northridge.

Contact:
818-677-2578 (V/TTY)
818-677-4929
ctrdis@csun.edu
http://www.csun.edu/cod

20th Annual PACRIM Conference on Disabilities
March 29–30, 2004
Honolulu, HI

The theme of the 2004 Pacific Rim Conference on Disabilities, “Promises to Keep, Futures to Seek” reflects on the promises and goals made and the opportunities created for persons with disabilities. It is sponsored by the Center on Disability Studies, University Center for Excellence, University of Hawaii at Manoa.

Contact:
Martha Guinan
808-956-9810
cds@hawaii.edu
http://www.pacrim.hawaii.edu/

Announcements

Sibling Support Project of the Arc of the United States

The Sibling Support Project is a national project dedicated to the concerns of the brothers and sisters of people with special health, developmental, and mental health concerns. The project specializes in providing workshops on family issues. It also sponsors email discussion groups for and about brothers and sisters of people with special health, developmental, and emotional needs. Both SibKids (for younger brothers and sisters) and SibNet (for older siblings) allow brothers and sisters an opportunity to connect with their peers from around the world. For more information visit the Web site at www.thearc.org/siblingsupport or contact:

Don Meyer, Director
6512 23rd Ave NW, #213
Seattle, WA 98117
206-297-6368
donmeyer@siblingsupport.org

United States & Canada Adopt New Braille Terminology

The Braille Authority of North America (BANA) announces a change in terminology to what has been traditionally known as “grade 1” and “grade 2” braille. These categories will now be referred to as “uncontracted” and “contracted” braille respectively. The change is being made at the request of many in the blindness field. People often confuse grades of braille with first and second grades in elementary school. BANA believes that the change to more accurately descriptive language will increase awareness and improve the overall understanding of how braille is learned, read, written, and transcribed.

Deaf-Blind Perspectives

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- 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 ____________________________

Please send my copy in:
- Grade 2 braille
- Standard print
- Large 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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