“What’s My Role?” A Comparison of the Responsibilities of Interpreters, Interveners, and Support Service Providers

Susanne Morgan, M.A., C.I., C.T.

Individuals who are deaf-blind access the world differently from their hearing-sighted peers. To ensure meaningful linkages to the environment and equal access to information, a variety of trained personnel and support persons are required. In recent years much attention has been given to the different roles that individuals play in providing this support.

The most familiar type of support is that provided by sign language interpreters. Formal interpreting services were established to meet the needs of deaf individuals. In recent years, these services have been expanded for persons with combined hearing and vision loss. This type of support, however, does not meet all of the unique communication needs of deaf-blind individuals.

Normal everyday life takes place in a variety of settings, including home, school, work, and recreation. For individuals who are deaf-blind, different settings require different types of communication supports. As the developmental, educational, and social needs of deaf-blind children and adults in these settings are better understood, the roles and responsibilities of support professionals evolve. Terms used to describe these roles, include interpreter, intervener, and support service provider (SSP). The following chart attempts to capture the current understanding of these roles and responsibilities.

<table>
<thead>
<tr>
<th>Interpreter</th>
<th>Intervener</th>
<th>Support Service Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone who</td>
<td>Someone who</td>
<td>Someone who</td>
</tr>
<tr>
<td>Translates information from one mode or language to another (spoken language to sign language and vice versa)</td>
<td>Intercedes between a child and the environment, allowing access to information usually gained through vision and hearing</td>
<td>Provides support that enhances independence (e.g., facilitating communication, providing sighted guidance, and transportation to/from events)</td>
</tr>
<tr>
<td>Works with deaf-blind people of all ages</td>
<td>Primarily works with children and young adults</td>
<td>Provides services to deaf-blind youth and adults who are able to make independent decisions</td>
</tr>
<tr>
<td>Is a conduit through which information flows</td>
<td>Facilitates learning and the development of skills (e.g., receptive and expressive communication, interactive behavior)</td>
<td>Facilitates interaction between a deaf-blind person and the environment</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Interpreter</th>
<th>Intervener</th>
<th>Support Service Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone who</td>
<td>Someone who</td>
<td>Someone who</td>
</tr>
<tr>
<td>May have received professional training in an interpreter-training program</td>
<td>May or may not have received specific training (however, training or coursework is recommended)</td>
<td>Is encouraged to receive basic training in the area of deaf-blindness, including communication strategies, sighted-guide techniques, and cultural issues</td>
</tr>
<tr>
<td>Should hold national and/or state certification/licensure and may have a college degree</td>
<td>Has varying educational and vocational experiences (some states offer coursework/certification)</td>
<td>Has varying educational and vocational experiences</td>
</tr>
<tr>
<td>Abides by a code of ethics</td>
<td>Acts in a manner that is governed by the local education agency and federal education laws Uses the Individual Education Program as a roadmap for learning Is considered a paraprofessional and works with, but does not replace, the teacher</td>
<td>Abides by standards established by the coordinating agency</td>
</tr>
<tr>
<td>Belongs to a national/regional organization of certified interpreters (e.g., Registry of Interpreters for the Deaf, National Association of the Deaf)</td>
<td>May or may not be in contact with other paraprofessionals</td>
<td>May belong to the coordinating agency’s network of SSPs May interact with other SSPs during local or national events</td>
</tr>
<tr>
<td>Will work in various environments (e.g., educational, medical, religious, social)</td>
<td>Works mainly in an educational setting but may also provide assistance in the community (e.g., daily living skills, medical situations, vocational environments)</td>
<td>Provides assistance in various settings, including the home and community</td>
</tr>
<tr>
<td>May be paid independently, through an agency or by an employer Is paid commensurate with certification &amp; local standardized fees</td>
<td>Is paid by the local education agency or a community provider</td>
<td>Is usually a volunteer, unless funds have been allocated</td>
</tr>
<tr>
<td>Is required to independently maintain certification through professional development</td>
<td>Is expected to attend workshops offered in educational settings</td>
<td>Is usually not required to attend further training but is encouraged to improve communication skills and interact with the deaf-blind community</td>
</tr>
<tr>
<td>Must remain impartial at all times</td>
<td>Wears “different hats” (e.g., as interpreter, guide, facilitator)</td>
<td>Remains impartial but has more flexibility than an interpreter</td>
</tr>
<tr>
<td>Must keep all information confidential</td>
<td>Is allowed and expected to share pertinent information with team members (e.g., parents, teachers, related service providers)</td>
<td>Is expected to keep information confidential</td>
</tr>
<tr>
<td>Is expected to keep a “professional” distance</td>
<td>Maintains an educational (teacher-student type) relationship</td>
<td>Is expected to act in a “professional” manner, but may develop personal relationships</td>
</tr>
<tr>
<td>Acts as a conduit (does not “teach” and is not responsible for ensuring that the deaf-blind individual learns what is being shared)</td>
<td>Is accountable for decision-making to enhance learning</td>
<td>Does not teach but does provide access to the environment to empower the deaf-blind person</td>
</tr>
<tr>
<td>Always keeps opinions to him/herself</td>
<td>Empowers individual to make his/her own decisions</td>
<td>May provide feedback/opinions when asked</td>
</tr>
</tbody>
</table>
References


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A Support Service Provider Program in Utah

Cordie Weed

There are not very many deaf-blind people in Utah. Compared to the number of people who have other disabilities, we are a small group, consisting of 150 adults. Services for adults who are deaf-blind are limited. Statewide, there is only one deaf-blind specialist and one part-time rehabilitation counselor. There are also interpreters, funded by the state legislature, for deaf-blind people who receive training at the Division of Services for the Blind and Visually Impaired or who wish to attend functions there or at the Division of Services for the Deaf or Hard of Hearing. These services are very appreciated, but they barely scrape the surface of the unmet needs of deaf-blind people in Utah.

Recently, however, a new service became available. Beginning July 1, 2001, the state legislature funded a support service provider program. For two years, two of my blind friends and I went to the state capital in Salt Lake City. As members of the Legislative Coalition for People with Disabilities, we asked the legislature to fund a support service provider (SSP) program for deaf-blind adults. We spent many hours talking to the legislators. We also contacted them by phone and mail and inspired others to call and write letters. We let them know that we wanted to be more independent and to live in our own homes. We asked for funding for the SSP program, and we got it.

For many deaf-blind people, life can be pretty empty and lonely. For example, one man who was born deaf-blind and who is in a nursing home has no way to communicate with the staff there. They do not know sign language or how to speak to him. There is no way for him to get involved in activities. He just sits in a chair all day with absolutely nothing to do.

There is also a woman whose family wants to put her in a nursing home because they do not want to care for her. They feel that they cannot cope with her needs. Instead, she chose to move into a housing complex for people who are disabled or have low incomes. This woman is unable to do her own shopping or care for her personal business. She cannot drive herself anywhere. She needs help to be able to live independently.

I know a man who was born deaf and spent most of his years in the deaf community. As he got older, he lost his sight and was unable to continue working. He is now totally blind. Recently, he and his deaf wife went to a social activity at the Deaf Center. He sat there and was bored because he could not see the sign language being used and no one thought to sign in his hands. When he and his wife left, he asked his wife if she had seen the man who had been his dearest friend for many years. She told him that he had been sitting next to him all evening. His friend had not said one word to him and the man was heartbroken.

Some deaf-blind people live in their own homes and are married and have children. Even though their families take care of them, they would still like to have someone take them out for social activities away from the family, to give them a change and to give the family a rest.

I am considered deaf-blind myself. I live in my own home and have a husband and two children. My daughter is married and has a baby. My son is grown but still lives at home. Both of my children grew up coping with my disabilities. I have Usher Syndrome. I am severely hard of hearing and have very little remaining vision.

Even though my family has lived with my increasing disability, they grow impatient and frustrated when I cannot hear or see something. I do not always hear exactly what they are saying, so communication is difficult and misunderstandings frequently occur. My husband has been forced to take on more responsibilities because I cannot shop by myself or travel alone on public transportation. These problems will only increase as my condition worsens.

I love to hear what is being said. I love to be a part of it all, but I am not because I cannot hear or see. I am left out a lot, and it is very lonely. Whenever I get frustrated, I cannot walk out or go somewhere to work it off. I have to stay put until it builds to the point where I explode. Sometimes I feel like I am in a box where I cannot move or let out my frustrations. I was raised to be independent and to take care of a family as well as myself. I want to continue to do that.

I would like the SSP to help me become more independent—to help me shop and walk my dog (a purebred beagle), to read my mail and other correspondence to me, to be my eyes and ears at social activities, and to take me to my appointments. This would also help by taking some pressure off of my family members. It means so much to me to be able to do more for myself. It makes me feel more like a human being.

We deaf-blind people need service providers. We need help with daily living in order to be independent. It is so much cheaper to have a support service provider than to be put in a nursing home. A support service provider can be a friend to a deaf-blind
person and can make the person’s life brighter. SSP’s assistance can also make it easier for family members by helping to relieve frustration and stress.

I really hope this program will work well for me, for others who are deaf-blind, and for the children who will soon become adults. I hope we will have this program for many years and that it will be successful. I want to make it work and help deaf-blind adults be independent and live happily. I feel very strongly about this program.

Valued Outcomes for Students Who Are Deaf-Blind and Their Families: Results of a Survey of State Deaf-Blind Projects

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Nora O’Farrell
San Francisco Unified School District

Are schools effectively meeting the educational needs of their special education students? Answers to this question can be provided from a variety of perspectives. A federal law, the Government Performance and Results Act of 1993 (GPRA) [Public Law No. 103-62], requires federal agencies to improve program effectiveness and public accountability by focusing on results, service quality, and customer satisfaction. It requires the establishment of measurable goals that can be reported as part of the federal budgetary process. In response to GPRA, the U.S. Department of Education’s Office of Special Education Programs (OSEP) developed guidelines for special education programs that list objectives and performance indicators for these objectives (Office of Special Education Programs, 1999).

The uniqueness of the abilities and needs of deaf-blind children poses challenges for the creation of outcomes and tools that measure those outcomes. To determine ways in which the OSEP guidelines could be made more meaningful and reflective of the specific educational needs and goals of deaf-blind children, we developed a questionnaire for state deaf-blind project personnel. It asked respondents what they considered to be valued outcomes for deaf-blind students, their families, and state and local systems that provide services. We defined a valued outcome as a result of the schooling process that is both individualized and perceived as positive and desirable. The development of social interaction skills in greeting peers or advocacy skills in promoting inclusive schooling to a PTA group are examples. The questionnaire also asked respondents to identify tools and strategies used to measure these outcomes.

Results of the Questionnaire

In 1998, the questionnaire was sent to the fifty existing state deaf-blind projects across the country. These projects are federally funded training and technical assistance entities serving schools, agencies, and families of deaf-blind children and youth. Project staff members were in a position to identify outcomes that address the different perspectives of groups and individuals involved in the lives of children and youth who are deaf-blind. Twenty-nine of the fifty questionnaires were returned, a response rate of 58 percent.

The questions were brief and open-ended and did not require respondents to use a specific format. Answers ranged from single words, phrases, and numbered lists to sentences and paragraphs. Given this diversity in format, the answers were analyzed by two independent raters and summarized in categories of valued outcomes (see table). The categories enabled a succinct synthesis that highlighted major focus areas for students, families, and systems.

The raters developed ten categories of valued outcomes for students, eight for families, and five for system-level entities. In addition to identifying specific valued outcomes, several state projects noted that, ideally, valued outcomes for students and families should be developed on an individual basis. Others commented that valued outcomes for deaf-blind children and their families are no different from those for children without disabilities.

In each of the three focus areas (student, family, system), certain responses were mentioned repeatedly by several respondents. Although the number of responses in each category is but one indicator of importance, it is an indication of the valued outcomes that are in the forefront of the respondents’ consciousness. The ideas expressed most often in each category are discussed further in this section.

Growing concern with the value and meaning of available interventions and services is reflected in all of the responses. Meaningful participation of the deaf-blind individual at home, school, and in the community is a recurring theme.
Student Outcomes. “Communication skills” and “social skills and friendships” were mentioned repeatedly as valued goals for students. Several respondents stressed the importance of communication skills that are functional and work across different environments (e.g., both at home and at school). Some respondents stressed the importance of the quality of relationships. They noted that there is a difference between relationships with paid staff and those that occur with friends and family, and they emphasized the need to ensure that relationships are mutual and long lasting.

Effective communication and good social skills are important elements for success in school environments. The stress on functional communication and meaningful friendships reflects the outcomes-based planning emphasized in the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA). There has been considerable progress in the development and refinement of interventions designed to improve the social interaction and communication of students with disabilities in regular education settings (Hunt, Farron-Davis, Wrenn, Hirose-Hatae, & Goetz, 1997; Odom, McConnell, & McEvoy, 1992; Strain & Kohler, 1995).

Family Outcomes. The availability of family-specific training was the most frequently mentioned outcome category for families. Respondents identified a need for training in the following areas:

1. Specific skills to support the child’s development, such as adapting environments and materials and learning communication skills and techniques;
2. Awareness of available resources;
3. Advocacy skills.

System Outcomes. System outcomes describe results that affect the structures and activities of organizations rather than individuals. Responses emphasizing collaborative planning for organizations were the most commonly identified valued outcomes. The involvement of parents and children in a collaborative planning process fosters smooth transitions and the achievement of independence for students. Parental involvement in educational program and transition planning has also been found to positively affect students’ academic outcomes (Morningstar, Turnbull, & Turnbull, 1995-1996; Everson & Moon, 1987; Sales, Metzler, Everson, & Moon, 1991).

Infrequently Reported Responses. Equally interesting and worthy of further research are the categories that received the least attention from respondents. Only a small number of respondents mentioned academic skills and self-advocacy as valued outcomes for students. Only a few mentioned empowerment as an important outcome for families or for inclusion as a system-level outcome. Empowerment and inclusion have received a great deal of attention in the general literature on special education (Dunst, Trivette, & Deal, 1994; Falvey, 1995). It is surprising that they received such scant attention here.

### Categories of Valued Outcomes

<table>
<thead>
<tr>
<th>Student Outcomes</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social skills and friendship</td>
<td>25</td>
</tr>
<tr>
<td>Inclusion into community</td>
<td>16</td>
</tr>
<tr>
<td>Communication skills</td>
<td>16</td>
</tr>
<tr>
<td>Self-help and independent living skills</td>
<td>15</td>
</tr>
<tr>
<td>Work/Career</td>
<td>14</td>
</tr>
<tr>
<td>Health, vision, and hearing</td>
<td>12</td>
</tr>
<tr>
<td>Recreation and leisure</td>
<td>8</td>
</tr>
<tr>
<td>Transition</td>
<td>6</td>
</tr>
<tr>
<td>Academic skills</td>
<td>5</td>
</tr>
<tr>
<td>Self-advocacy</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total Student Responses</strong></td>
<td><strong>121</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Outcomes</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-specific training</td>
<td>20</td>
</tr>
<tr>
<td>Valued member of family and community</td>
<td>15</td>
</tr>
<tr>
<td>Resources for adult independence</td>
<td>14</td>
</tr>
<tr>
<td>Resources for families</td>
<td>12</td>
</tr>
<tr>
<td>Family stability</td>
<td>8</td>
</tr>
<tr>
<td>Connections for families</td>
<td>8</td>
</tr>
<tr>
<td>Family/professional collaboration</td>
<td>6</td>
</tr>
<tr>
<td>Empowerment of families</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total Family Responses</strong></td>
<td><strong>86</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>System Outcomes</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative planning</td>
<td>30</td>
</tr>
<tr>
<td>Staff availability and training</td>
<td>18</td>
</tr>
<tr>
<td>Resources for community inclusion</td>
<td>17</td>
</tr>
<tr>
<td>IEP/IFSP quality</td>
<td>13</td>
</tr>
<tr>
<td>Range of educational placement options</td>
<td>10</td>
</tr>
<tr>
<td>Inclusion</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total System Outcomes</strong></td>
<td><strong>93</strong></td>
</tr>
</tbody>
</table>
**Assessment Issues**

The IDEA Amendments of 1997 place great emphasis on measuring results through improved accountability and data collection efforts. There is a renewed reliance on the use of assessments to measure the performance of students and their progress toward meeting identified standards. In responses to our questionnaire, we identified a total of eighteen assessment tools and measures, including several curricula and informal methods of data collection such as case studies and interviews. No tool was mentioned with sufficient frequency to be representative of the responses.

**Conclusion**

The OSEP guidelines describe objectives in general terms such as “improve educational results for children with disabilities.” The results of the questionnaire reported here reflect how state deaf-blind project personnel interpreted these objectives in terms of actual practice with students, families, and service providers. For example, development of communication skills and social skills and friendship emerged as key elements for the objective of improving educational results.

There are a couple of limitations to the results of this study. First, the 58 percent response rate limits the generality of the findings. A further limitation is that the questions asked were very brief. A more detailed survey or the use of focus groups would add to the depth of the information that could be obtained.

The development of valued outcomes for students, families, and systems can have direct implications for the evaluation of programs serving students who are deaf-blind and their families. Programs, services, and technical assistance efforts that are consistent with the valued outcomes reported here will strengthen the alignment between actual practice and the goals of those who assist and support practitioners working with deaf-blind children. Further study and development of valued outcomes for deaf-blind students and the creation and use of tools to measure progress towards educational goals should be a priority for the field.

**References**


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**Helping Children Cope With Grief: A Discussion of Options for Parents of Deaf-Blind Children**

Compiled by Nancy O’Donnell

Helen Keller National Center

When it comes to parent/child dialogues, there are few topics that cause as much anxiety as sex and death. When those topics are considered in the framework of discussing them with children who are deaf-blind, many families and professionals are left speechless.

Early this year, I received an e-mail from a mother in New Zealand who was looking for guidance on how to help her son grieve the loss of his grandfather:

Hi Nancy,
From a mother in New York:

A little over a year ago we lost five family members in one month — my grandmother, two uncles, a cousin, and my brother whom [my daughter] was very close to — then her cat. It was very hard to really know what she was feeling. She doesn’t have tears and I never know if she’s crying. She would stay in her room, sitting in the chair [and] holding a stuffed animal to replace the cat, or she was in the bed asleep. The staff [at the center she attends] was very helpful because she was able to communicate what she was feeling to someone there. I still am not sure how she is dealing with grieving, but she seems to be doing all right. As a mother, I want to fix everything, but I can’t. I need all the help I can get.

From a professional in Massachusetts:

One of my students who is deaf-blind lost her father last fall. We recommended creating a visual schedule of events (wake, service, funeral, pictures of relatives who will be attending the events, etc.) for the days just after the death. The mother also discussed the death and all the events with her and [put together] a photo album [for her daughter to bring back to her program]. Her mother said that our recommendations were helpful and that the daughter was dealing quite well with her grieving. The daughter was back to her regular
schedule on the third day, and she was fine with it.

Keeping busy and getting up and around is an important part of a grieving process. Having regular scheduled events related to the family member who has passed away is also important (special church related memorial activities, grave visits, conversations that are supported by visual or tactile aids, small family ceremonies according with the family traditions, etc.). Talking is helpful but [some] deaf-blind people need concrete objects and specific actions to support them in their grief.

What kind of support is the mother getting at this point? She has lost her father, and she is going through a rough time herself. She has my sympathy, and I hope that she is taking care of herself too.

From a professional in Texas:

Personally . . . I don’t trust language too much on this stuff. Demonstrating the rituals that we pursue is where you get started. Who knows what each individual soaks up from these traditions? Much of this is individually tailored . . . even in our hearing-sighted world. Much instruction about death is learned through observation of daily life, and for children it often begins with the passing of a pet. When I was young, we kids, with no suggestions or involvement by my parents, had funeral ceremonies for our pets, complete with little crosses which symbolized to us the protection of the spiritual world. Did we know what the crosses meant? Not really. But the purpose was served.

I think that having a deaf-blind person take part in some aspect of the rituals of their family is what brings them into the experience. It is up to each family to creatively find the best way to become part of the experience. Participation in the ritual is not just for the person . . . but for everyone connected to the person. Death engages us in an experience of closeness with community. Since language is so inadequate, we prescribe rituals to help us experience (celebrate) the needed communion of our lives.

I wonder about the handling of objects which the person used. I personally have such objects, which I keep in a personal “shrine.” Perhaps it would be possible to place such objects in a memory box that could be visited to remind the person of the individual they lost. They may be able to relate this to memory boxes, etc., that they have about places they have been.

From a professional in New York:

There is no reason why a person with deaf-blindness will not experience loss as profoundly as everyone else. Some time ago, Elizabeth Kubler-Ross outlined stages of grief. . . . It was once thought that everyone had to go through those stages in order. Now, years later, we know that is not true, and that there are other aspects of grief. . . . For a person with limited formal language, the process of explaining what has happened and listening to their feelings can be complicated. The important part is to be there with them and listen empathically. It is especially important that the family and other support people have a common understanding of the language they are using to explain what has happened. For example, has the grandfather “died,” “gone to heaven,” etc. It would also be important, especially when the deaf-blind person has had a close relationship with the one who has died, to try to understand if they feel in any way responsible or if they have any unfinished business.

As far as how long to allow them to be depressed, idle, sleep, etc., recognizing the feelings of sadness does not mean wallowing in it or allowing it to interfere with the quality of the individual’s life. It would be important for the other family members and support people to encourage good nutrition and activity, short walks or favorite outings, etc., while still acknowledging that everyone is sad for their loss. Sometimes, grieving people feel that having fun is a betrayal to their loved one. Time heals, but there is no set amount of time. Also, all those feelings will emerge at different times and be triggered by different events, places and people.

It sounds to me like this young man is very lucky to have such a sensitive and caring mother, who is concerned about him, while grieving herself. I commend her.

From a parent in Washington State:

I have been thinking about the several deaths in our family and trying to recall my daughter’s reactions. The person she was closest with was my father, who died when she was six. She attended residential school then. Dad died a week before school began so she was not with her family in the weeks right after he died. On the day he was buried, we selected a plant from the funeral service. We took it to plant outside the window of her classroom. She helped plant it and tend it.

When a family member dies I have my daughter touch the deceased to feel the difference in his or her body. We talk about the things they have done together and that they won’t be able to do that any longer. We acknowledge that we are sad. I have included her in as many funerals and memorial services as reasonable so that she has first hand knowledge of the end of a loved person’s life. She now understands the meaning of death and knows that person won’t be there to do things with. I don’t know if she
Grief is a natural response to loss of any kind. I would be [suspicous] if there were no grief responses from this young man who has lost a grandfather. His mother is also grieving and her activities (described in her responses) with her son are exactly what they both need at this time. Both mother and son will find it hard in the beginning to define their feeling via language and that is all right. It will come later — just being there physically and sharing with each other quietly will help ease the pain and confusion. There is no time limit to be set on easing out of grieving. Continuing the activities that have been started between mother and son as well as some of the other suggestions will eventually lead to resolution.

From a mother in Missouri:
My son’s father died October 1999. A staff member, who was a very intuitive young man, took Paul to see his dad an hour before he passed. Paul felt his face and held his hand. The young man observed the very different expressions that were occurring on Paul’s face and said that on some level Paul knew what was happening.

Perhaps if there is a favorite object from the Grandfather, the young man could keep that as a remembrance. That might help.

And from another mother in Michigan:
After reading the responses on grieving, I decided to add our experience. [My daughter’s] father had been ill for many years. He was diagnosed with multiple sclerosis in 1976. For years, he was on a scooter, which she accepted as part of Dad. Later, when the hospital bed became a living room fixture, she knew Dad was there. She would walk over to him, [give him a] big smile, and shake little fingers as her greeting. When he was hospitalized, she’d feel the empty bed but be all smiles when he came home. He passed away at home in April of 1999. We showed her his body, had her feel his face, told her “Daddy bye-bye.” We took her to visitation, showed her dad again, saying “Daddy bye-bye.” Now, we didn’t know how this would register with her but the next morning, when she came into the living room and the hospital bed was gone, she started to sob. I have never before or since heard her sob that hard and long.

Something certainly clicked that morning and her siblings were amazed that she reacted that way. However, [there have been] no more reactions and no objections to going back to her program. As I’ve learned, we all grieve in our own way and our own time. We were all feeling sad and she probably had extra hugs from all of us.

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And so, dear readers, we’ve learned that grieving is grieving, whether you’re deaf and blind or sighted and hearing. Everyone does it in their own way, in their own time. There are things that can be done to help the process along, to make it more practical and real, but ultimately, death and loss mean different things to different people. Some of us need more hugs, others need more space. Some of us want to remember, others want to forget. But we all need to be...
Corrina Veesart, a nineteen-year-old woman who is deaf-blind and her mother Pearl. Corrina and Pearl live in Los Osos, a small community located along the central coast of California. Pearl also has a son, Ryland, who is seventeen. Corrina recently graduated from high school. Pearl works as a professional gardener and landscaper. I talked to Pearl and Corrina about Corrina’s educational experiences, her plans for the future, and their feelings about services for deaf-blind people.

Pearl first noticed that Corrina had difficulty seeing and hearing when Corrina was very young. The cause of her deaf-blindness has never been diagnosed, although she has been evaluated by numerous specialists. Initially her hearing loss was believed to be due to central auditory processing disorder, but she was found to be deaf when she was eight years old. Both her hearing and vision loss have been progressive.

Pearl says that obtaining the educational services Corrina needed was often a struggle during Corrina’s school years. She learned to be an effective advocate by educating herself in areas of special education law and issues pertinent to deaf-blindness. She has found the network of resources and professionals within the field of deaf-blindness to be invaluable and believes that combining knowledge about the law with those resources can be a potent means of accessing and creating quality services. In this manner she was able to obtain services for Corrina in high school that included a special education teacher with experience and training in deaf-blindness, interpreters, Braille and orientation and mobility instructors, technical assistance and training for specific program needs, and inclusion in typical classrooms. Pearl points out that although special education laws have existed for many years, they aren’t always implemented. She believes that it is important for people collectively and as individuals to stand up for their special education rights in order for the implementation of those rights to become commonplace.

Pearl says that her ongoing encounters with the educational system had an impact on her own personality. Although she used to be very shy and easily intimidated, by educating herself and being supported by various professionals, she became empowered and began to feel more confident and assertive. She says that she found her own voice in the process of advocating for Corrina and broke through barriers in herself. She became a healthier and more capable person.

Corrina is both excited and overwhelmed at the prospect of transitioning from school to college and a new life. She echoes her mother’s assessment of her school years, when it was often difficult to get what she needed. She says that she is “sick of all the meetings” associated with getting services and would rather be involved in more normal teenage activities.

Corrina can hear an occasional loud sound, but not speech. She also has some vision. She can see a little up close (within five to six inches of her face), but beyond that things are blurry. She says, “I can see shapes further away and often can identify them if I already have an idea what they are. From my window there are two trees in the front yard. I can see the trunk. I can see up to where the leaves are, but I can’t make out details. Suppose a bird or a bird’s nest is in the tree. I can’t tell that unless someone tells me.” Corrina mostly uses her vision to see sign language, but says that her eyes get very tired. She feels that her vision is getting worse and she is shifting to tactile sign language.

Corrina plans to go to junior college, but is taking a break from school this fall semester and working instead. She has a part-time job as a teacher’s aide in a first grade class. She loves children, especially babies. She might be interested in a career that involves working with children, but she has numerous interests and at this point in time doesn’t know what type of career she will pursue. In high school she enjoyed
many subjects, including English, science, and art. She was also a cheerleader for two years.

Corrina loves to read and does so using Braille and large print with a magnifier. She also likes ballet, aerobics, and although she can’t hear very well, she enjoys music if she’s able to be included through touch. She has friends who are musicians. They let her feel their throats and instruments when they play and sing. During this past summer she took a lot of dance and exercise classes, hung out with her friends, went to visit her dad in Alaska, and attended the Seattle Lighthouse for the Blind deaf-blind retreat.

Corrina says that more than anything she wants space and independence. She says that she can do a lot already, but needs to learn more skills like housekeeping, food shopping, and traveling alone. She wants to be as independent as possible but says that she feels frustrated because, “It seems to be happening so slowly and I feel penned up. I still need to learn so much.”

I asked Pearl and Corrina about the current state of deaf-blind services and what they think is important for the future. Both told me that access to interpreters who have the education and experience necessary to interpret for deaf-blind people is very important. They believe that interpreters for deaf-blind people should receive specialized training and recognition.

Pearl had a number of additional observations and suggestions. She said that high-quality assessments are critical because they determine the types of educational services that children receive. She believes that assessments should be performed by people with expertise in deaf-blindness and that parents have a meaningful role in the assessment process. She would like to see quality options for assessment and training available in local communities and says that it is essential to maintain funding of programs and research dedicated to the deaf-blind population.

Pearl said that while she is grateful for the services that are currently available, she believes that there is still much to do to improve the quality of life for deaf-blind people. She says that there needs to be a balance between gratitude and acknowledgment for what the deaf-blind community has and continued efforts to strive for something more. She also says, “Deaf-blind people should have a life with the kind of choices and opportunities that any of us have. That’s what Corrina and I are heading for.”

On August 2-4, 2001, in Miami, Florida, a gathering of nearly 150 parents from the United States and Latin America attended An International Celebration of Empowerment: Sharing Dreams and Visions for Children and Young Adults Who Are Deaf-Blind, sponsored by the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), along with the National Family Association for Deaf-Blind (NFADB), the Hilton/Perkins International Program, and Foundation ONCE (Organización Nacional de Ciegos Españoles).

The workshop offered a unique opportunity for parents and family members from the United States to exchange perspectives on empowerment and self-determination with parents and families from fourteen Latin American countries. Workshop activities were designed to enhance the capacity of participants to discover and fulfill the dreams of their children and other family members.

Throughout the two-and-a-half days of the meeting, parent and deaf-blind presenters from both hemispheres shared stories about making their dreams come true, the critical need for person-centered planning, and strong collaborative partners, as well as about the importance of balancing the child’s dream within the context of the family’s dream.

Despite the differences in cultures and backgrounds, parents quickly connected with one another, understood each other’s problems and fears, delighted in one another’s successes and achievements, and recognized that parents share a universal perspective when it comes to dreaming for their children who are deaf-blind.
For Your Library

A CD-ROM that demonstrates assessment techniques developed by Dr. Jan van Dijk. Includes approximately 40 videoclips of deaf-blind children between two and seven years of age. The CD-ROM is interactive allowing the viewer to test his or her knowledge of a subject. The cost is $50.00. Profits will go into a fund to finance the production of similar materials in the future. Dr. van Dijk says U.S. orders can be sent in care of his brother-in-law, Mr. Joe Franken, 4619 Spysglass Drive, Dallas, TX 75287. Make the check payable to Mr. Joe Franken. Dr. van Dijk’s e-mail is j.vdijk@ivd.nl

A collection of writings by people who have been involved in the lives of children and young adults with severe disabilities and deaf-blindness. Topics include self-determination, collaboration, assistive technology and positive behavioral supports. Available from: Jeff Cook, Kansas Project for Children and Young Adults Who Are Deaf-Blind, Kansas State Department of Education, 120 SE 10th Ave., Topeka, KS 66612-1182. TTY: 785-296-0917. E-mail: jcook@ksde.org

These competencies address the knowledge and skills that a paraprofessional must have in order to assist in implementing quality programs and enhance the quality of life for learners who are deaf-blind. The cost is $5.00. Available from Public Relations and Publications Department, Perkins School for the Blind, 175 N. Beacon St., Watertown MA 02472. Phone: 617-972-7328.

Two biographies of Laura Bridgman were recently published. Laura Bridgman was a deaf-blind woman who was born in 1829 and lost both her sight and hearing due to scarlet fever at the age of two. She began attending the Perkins School for the Blind at the age of seven, where she was educated under the direction of Samuel Howe. Both books describe her life, including her education, her complex relationship with Howe in the context of the rapid social and cultural changes that were occurring in 19th-century Boston. Available through bookstores.

FOCUS (Full Option Curriculum for the Utilization of Social Skills) consists of five modules related to helping children who are visually impaired develop social skills. Each set contains a videotape and self-directed study guide. Individual titles: Importance and Need for Social Skills, Assessment Techniques, Teaching Social Skills to Visually Impaired Preschoolers, Teaching Social Skills to Visually Impaired Elementary Students, Social Skills for Teens and Young Adults with Visual Impairments. Each set costs $59.95. Available from AFB Press, Customer Service, P.O. Box 1020, Sewickley, PA 15143. Phone: 800-232-3044. Website: http://www.afb.org/afb_press.asp

This packet of information was developed for parents to pass on to their children’s teachers (or for teachers to request themselves). It includes fact sheets, newsletters, lists of articles about communication, curricula, and environmental considerations, and a brochure and article that describe DB-LINK services. Available from DB-LINK. Phone 800-438-9376. TTY: 800-854-7103.
Email: dblink@tr.wou.edu
Website: http://www.tr.wou.edu/dblink
**Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed.**

*Moss, Kate & Blaha, Robbie. Monmouth, OR: DB-LINK, 2001.*

A book for parents and professionals, this new text offers information and instructional guidance for delivering sex education to deaf-blind students who also have cognitive disabilities. Issues of self-expression related to gender identity, modesty, and appropriate touch are discussed. Specific instruction is included for menstruation, masturbation, hygiene, health, and sexual abuse. Available on the web or by contacting DB-LINK. Phone 800-438-9376. TTY: 800-854-7103. E-mail: dblink@tr.wou.edu

Website: http://www.tr.wou.edu/dblink

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**National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives (NTAC Briefing Paper).** *Petroff, Jerry G. Monmouth, OR: The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind, 2001.*

This paper describes the results of a study that surveyed parents of deaf-blind youth (age 18-24) who had already left school, to find out about their children’s post-school experiences relating to education, employment, living arrangements, and community involvement. Available on the web (http://www.tr.wou.edu/ntac/publications.htm) or by contacting DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: dblink@tr.wou.edu

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Research to Real Life presents snapshots of eight research-to-practice projects on deaf-blindness. The projects included research in early intervention, assessment, education, inclusion, communication, technology, behavior, and self-determination. Available from DB-LINK. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: dblink@tr.wou.edu

Website: http://www.tr.wou.edu/dblink

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**Who Cares?: Access to Healthcare for Deafblind People.** *Sense and Deafblind UK, 2001.*

This report is based on a major national survey in the United Kingdom of deaf-blind people’s experiences of health care. It outlines actions required to ensure full and equal access to health care for deaf-blind people. Available on the web at:

http://www.sense.org.uk/campaigns/health.html

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**Announcements**

**Call for Art Work**

The Helen Keller International Art Show sponsored by the Council for Exceptional Children Division on Visual Impairments and the University of Alabama at Birmingham Vision Science Research Center invites youth who deaf-blind, blind, or visually impaired to submit art work. Students may select the preferred art medium. The contest is open to students of all ages.

Art must be submitted by February 1, 2002. The winning entries will be exhibited, beginning with the CEC International Conference in New York City, April of 2002. For more information and to obtain entry forms contact UAB Vision Science Research Center. Phone: 866-975-0624. Fax: 205-934-6722. E-mail: Msanspree@icare.opt.uab.edu

**National Federation for the Blind Deaf-Blind Division**

The NFB Deaf-Blind Division is an organization of deaf-blind persons working nationally to improve services, training, and independence for deaf-blind people. They offer personal contact with other deaf-blind individuals knowledgeable in advocacy, education, employment, technology, discrimination, and other issues surrounding deaf-blindness. For more information visit the web site at http://www.nfb-db.org or contact:

Joseph B. Naulty, President
561-753-4700
jbnaulty@adelphia.net

Kimberley Johnson, Treasurer
Colorado Center for the Blind
2233 West Shepperd Avenue
Littleton, Colorado 80120
303-778-1130 (ext 212)
eclipse@interfold.com
Conferences

Fall 2001

Conferences

The Active Learning Approach: An Educational Approach Facilitating Development and Learning in Children with Multiple Disabilities

Presented by Lilli Nielsen, Ph.D.
November 12-14, 2001
Los Angeles, California

The philosophy behind the active learning approach is that, if given an opportunity to learn from exploration and examination, a child can become an independent active learner. This conference, sponsored by the Infant Development Association of California, in cooperation with WestEd Center for Prevention and Early Intervention will include information about active learning techniques, modifications to the learning environment, and an introduction to perceptual aid equipment. Participants will learn how to give children opportunities to help them develop basic skills in spatial relations, motor development, and emotional and cognitive development. Family members and all early childhood professional disciplines are encouraged to attend.

Contact:
Infant Development Association of California
Phone: 916-453-8801
Email: idaofcal@softcom.net

Eighth Annual Regional Conferences on Improving America’s Schools

Three regional conferences by the U.S. Department of Education are scheduled for the Fall of 2001. One has already taken place, but there will be one in Reno, Nevada, November 13-15, and another in San Antonio, Texas, December 17-19. Goals for the conferences include making it possible for participants to gain an understanding of the Department’s new priorities and initiatives, learn about the latest research and data, receive information about funding opportunities, and interact and share ideas with Departmental staff.

Contact:
U.S. Department of Education
Washington, DC, 20202-6100
Phone: 800-203-5494
Web site: http://www.ncbe.gwu.edu/iasconferences
Email: ias_conference@ed.gov

2001 TASH Conference: Imaging the Future
November 14-17, 2001
Anaheim, California

The TASH conference will include more than 300 sessions on issues that affect the lives of people with disabilities, with a particular focus on those who have severe or multiple disabilities. Panels of presenters include people with disabilities, parents, educators, researchers, and direct support professionals. There will also be exhibits by representatives of many of the leading disability-related manufacturers, publishers, and suppliers.

Contact:
Kelly Nelson
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
Phone: 800-482-8278 ext. 105
Email: knelson@tash.org
Web site: http://www.tash.org

Zero to Three
16th National Training Institute
November 30-December 2, 2001
San Diego, California

The National Training Institute is designed to challenge participants with new ideas and approaches, to provide an opportunity to form connections with others in the infant/family field, and to inspire practitioners in their work with infants, toddlers, and their families. A pre-Institute is scheduled for November 29th.

Contact:
Meeting Management Services/ZTT
1201 New Jersey Avenue, NW
Washington, DC, 20001
Phone: 202-624-1760
Web site: http://www.zerotothree.org

Autism and Children with Visual Impairment Workshop
Macon, Georgia
February 14-15, 2002

This workshop featuring Marilyn and Jay Gense is being co-sponsored by the American Printing House for the Blind and the Georgia Academy for the Blind.

Contacts:
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The American Printing House for the Blind, Inc.
P.O. Box 6085
Louisville, Kentucky 40206-0085
Phone: 502-895-2405
Email: jhumphries@aph.org
Web site: www.aph.org

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Phone: 478-751-6096
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✓ Higher education teacher/researcher
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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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