

Deaf-Blind Perspectives

Project SALUTE Information Sheets A Field Test of the Spanish Translation in Puerto Rico

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Children who are deaf-blind need a variety of communication options that foster natural social interactions and conversations. Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively), a model demonstration project funded by the U.S. Department of Education to California State University, Northridge, from 1999 to 2004, was created to address the unique learning needs of children who require a tactile mode of learning. One result of the project was the development of 12 information sheets describing tactile learning strategies. Each information sheet includes the definition of a strategy (e.g., object cue), considerations in the use of the strategy, and its advantages and disadvantages. The information sheets are well organized and easy to read.

To accommodate the large number of Spanish-speaking families in the United States, the information sheets were translated by the bilingual coordinator of Project SALUTE, who is from Costa Rica, and were reviewed by bilingual service providers and Spanish-speaking families in California, who were from Mexico and a number of Central American countries. There are, however, multiple lexical and semantic variations of the Spanish language used by Hispanics. In order to determine the usefulness of the information sheets in Puerto Rico, Project SALUTE collaborated with the authors of this article to field test the Spanish version with families and teachers.

Deaf-Blind Education in Puerto Rico

Puerto Rico is a territory of the United States where the main language is Spanish. The population is 3.8 million, of whom less than .01% are deaf-blind. In 2003 the Special Education Program of the Puerto Rico Department of Education had 66 deaf-blind students registered, ranging in age from birth to 21 years (Departamento de Educación, 2003). Prior to 1999, most of the deaf-blind students in Puerto Rico were served in a segregated program in a hospital setting at the Ruiz Soler Hospital in Bayamón, near the San Juan metropolitan area. At the age of 21, students continued in a private transitional program in the same hospital. There were limited occupational expectations for these students, in part because of a lack of communication skills.

Following the implementation of a federally funded project, the Deaf-Blind Program of the Department of Education in Puerto Rico, the educational placement of deaf-blind students shifted from a segregated model to a more inclusive one. In August 2003 when the school year started, 34 of the students were placed into inclusive programs in regular schools throughout the island. Two very young children were placed in special early-intervention centers in inclusive schools. An additional 10 children were educated at home because of medical conditions. Only 20 of the 66 remained at the program in Ruiz Soler Hospital.

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To serve students who are deaf-blind with different skills in different settings is a big challenge. Communication is the most needed skill identified in the individualized education programs (IEPs) of the deaf-blind school-age students being served in Puerto Rico. Teachers have also expressed their need to learn strategies to teach communication skills and have identified communication as the primary area in which they need technical assistance (Adorno-Oquendo, 2002; Rodríguez & Sanabria, 2003).

Field Testing

Because the teaching of communication skills was recognized as the most critical training need and because information about deaf-blindness in Spanish is limited, testing the Project SALUTE information sheets was an option worth trying. The field testing was conducted by Juanita Rodríguez, a consultant to the Deaf-Blind Project in Puerto Rico, and Marta Sanabria, deaf-blind project coordinator, and it was designed to answer two questions: Were the information sheets linguistically and culturally appropriate for Puerto Rican families and teachers and which information sheets were used most frequently and why?

Seven parents and ten teachers involved with children of different age ranges were selected to participate. In four cases, both the parents and teachers of a single deaf-blind child participated. The parents and teachers were encouraged to share with one another their experiences and the children's reactions and responses to the strategies presented in the information sheets.

The consultant and the coordinator met with the participants on two occasions. The first meeting was to explain the purpose of the field testing

and what was expected of the participants. Each of the information sheets was explained, and role-playing exercises followed to make sure the strategies were understood. Participants were encouraged to read them again and to select and use as many as they could apply to their children's specific communication needs. They also were asked to keep notes of their experiences and comment on the appropriateness of the use of Puerto Rican Spanish in presenting the information.

A second meeting, organized as a focus group, was scheduled three weeks after the first. Three of the 10 parents had dropped out of the project. All 10 teachers completed the task. The participants were asked to respond to two questions and share their experiences and recommendations.

Results

In response to the question about the linguistic and cultural appropriateness of the information, the most frequent comment of both parents and teachers was that "it was in Spanish." Parents in Puerto Rico are often confronted with the fact that there are limited resources, books, manuals, and guides in Spanish, and they lack the language competence to benefit from materials that are written in English. The participants found the translation to be appropriate, but they did observe that the information sheets contained a few words that are not used in Puerto Rico. For example, the word *excita* (get excited) is not used in Puerto Rico. Instead, *emociona* is used. The word *pastel* for cake has a different meaning in Puerto Rico. It is a special dish made out of vegetables. The Puerto Rican word for cake is *bizcocho*. Another word with a different meaning is *pajilla* (drinking straw), for which Puerto Ricans use *sorbeto*. *Pajilla* is something made out of straw, like a type of chair that is crafted in

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Puerto Rico. Overall, however, less than 20 words in all of the information sheets needed to be changed to be responsive to Puerto Rican culture and language. The parents and the teachers said that it was great to have the information in Spanish.

In answer to the second question about which information sheets were used most frequently and why, participants indicated that those describing strategies previously used by teachers and parents tended to be the favorites. These were (in order of use): Object Cue, Tangible Symbols, Tactile Signing, Touch Cue, and Coactive Signing. Parents and teachers agreed that these five information sheets described strategies similar to the communication methods most often used by their children and students.

Participants also discussed the applicability of the information sheets in their daily interactions with the children. Parents reported that the information helped them to appropriately name communication strategies that they already used, which made it easier to refer to the strategies when talking to other parents or teachers. Because some of the information sheets suggest ways to develop portable communication devices, another benefit was the teaching of strategies to help children function beyond the family circle.

One of the mothers commented that she realized the importance of expanding her 14-year-old daughter's communication circle. Up until this experience, she never understood why family members would not babysit for her daughter. She now realized that it was because they did not know how to communicate with her. The information sheets provided this mother with a more organized and systematic way to learn how to communicate with her daughter and to teach her family as well.

The participants concluded the focus group discussion by recommending that the information sheets include

Project Salute Information Sheets

- ◆ Object Cue
- ◆ Touch Cue
- ◆ Communication Symbols
- ◆ Coactive Signing
- ◆ Sign On Body
- ◆ Tactile Signing
- ◆ Tangible Symbols
- ◆ Textured Symbols
- ◆ Tactile Communication Strategies
- ◆ Mutual Tactile Attention
- ◆ Tactile Modeling
- ◆ Emergent Literacy for Children Who Are Deaf-Blind

Available at
<http://www.projectsalute.net>

some visual cues to help them better understand each strategy. They felt that drawings and pictures would ease the reading and convey the information in a more meaningful way. Overall, they felt that the Project SALUTE materials allowed them to work in a systematic way to help their children develop communication skills and recommended their use with other deaf-blind children.

Summary

This field-test demonstrates the usefulness of linguistically and culturally sensitive Spanish language materials for parents and teachers and the need to develop more materials. It was also obvious that parents and teachers of students who are deaf-blind need more opportunities to dialog in an environment of respect and mutual understanding to achieve the common goal of providing appropriate education to this special population. The support that members of the focus group provided to each other while sharing their experiences, made the meetings worthwhile. Parents and teachers came to view one another as collaborators. It was understood that teaching communication skills to students who are deaf-blind is a responsibility not only of the family but of the school as well. Together and with access to helpful resources like the Project SALUTE information sheets, families and schools can achieve the goal of developing communication skills for children who are deaf-blind.

References

- Adorno-Oquendo, M. (2002). *Guía de adiestramiento en el área de sordociegos*. Unpublished master's thesis. University of Puerto Rico, Río Piedras, Puerto Rico.
- Departamento de Educación (2003). *Censo de sordo-ciegos (Child count)*. San Juan, PR.
- Rodríguez, J. & Sanabria, M. (2003). *Needs assessment of teachers of students who are deaf-blind*. Report presented to the Puerto Rico Department of Education, Special Education Program.



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Forty Years after the Epidemic HKNC Hosts an International Symposium on Rubella

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On March 21, 2005, the Centers for Disease Control and Prevention (CDC) announced that rubella had been virtually eradicated in the United States (CDC, 2005). This landmark declaration was presented via teleconference with all the fanfare and excitement that such an important statement deserves. We've come a long way since the 1960s, when 12.5 million cases of rubella occurred in the U.S. during a worldwide pandemic. This number is in sharp contrast to the nine cases reported in 2004, all of them "imported" from countries outside the U.S. This decline is a direct result of the introduction of the rubella vaccine in 1969.

The eradication of rubella is important because of the potentially devastating effects of rubella on a developing fetus. If a pregnant woman contracts rubella during the first trimester of pregnancy, her child can be born deaf, with vision problems, heart problems, developmental delays, and a host of other health issues. This constellation of symptoms is known as Congenital Rubella Syndrome, or CRS. As long as rubella immunization rates remain high, most babies will never experience the devastating effects of CRS. Although this news may prompt a collective sigh of relief, our work with rubella is far from over. The needs of the approximately 20,000 people who were born in the U.S. with CRS during the epidemic of the 1960s—many of whom are deaf-blind—are still significant. And sadly, despite the eradication of rubella in the U.S., the World Health Organization reports that, worldwide, as many as 100,000 babies continue to be born with CRS each year (WHO, 2000).

HKNC has worked with adults with CRS since the 1970s. In the late 1980s, parents of these adults started contacting us to ask about the possibility of additional medical problems emerging in this group. Researchers in Australia were the first to identify late-onset health concerns. Their longitudinal study of a group of 50 adults born during a rubella epidemic in Australia in the early 1940s showed high incidences of glaucoma, diabetes, and thyroid problems. In response to the parents who contacted us, HKNC surveyed a group of individuals with CRS here in the U.S. and found similar results. Since then, we have continued to

collect and disseminate information about CRS, but because of the dwindling numbers of people with CRS, the severity of their disabilities, the challenges of communication, and the diverse geographic distribution of the group, many professionals in the medical community and adult services lack experience with these individuals. Hoping to broaden our knowledge base and tap into resources internationally, HKNC and the CDC cosponsored an international symposium on rubella in mid-March. Representatives from 12 countries participated in this landmark event held at HKNC headquarters in Sands Point, NY.

Presenters included medical researchers, educators, and rehabilitation professionals. The symposium opened with a keynote by Paul Parkman, who was part of the team that first identified the rubella virus and developed the first rubella vaccine. He gave a compelling description of the atmosphere of urgency driving rubella research in the 1960s and of the incredible impact of the vaccine when he estimated that without the vaccine an additional 100,000 babies might have been born with CRS in the U. S. Other presenters included Australian researchers Margaret Burgess and Jill Forrest; Lou Cooper who worked with and studied many of the rubella babies born in the New York metropolitan area; Ed Hammer, who gave a brief overview of the early days of deaf-blind education; and Pam Ryan, psychologist at Perkins School for the Blind, who has observed and worked with children who are deaf-blind for 30 years. Betty Hedgecock, who has a 40-year-old son with CRS, gave a moving and informative description of what it has been like to raise a child with CRS. Betty is a nurse and has a unique perspective from both a personal and professional point of view.

Speakers from Africa, Argentina, the UK, Italy, Canada, Norway, and the Netherlands gave a brief overview of the rubella situation in their countries. Greece and SENSE Scotland were unable to attend but sent reports. We learned that there is great disparity in immunization rates from country to country. This led to a short but animated discussion about the controversy surrounding the link between autism and vaccines and the subsequent drop in immunization rates in a number of countries as a result of this controversy. Joseph Icenogle from the CDC gave an overview of the history of the rubella virus and of an upcoming research project. Rodrigo Rodriguez from the Pan American Health Organization discussed the goal to eradicate rubella from the Americas by 2010.

Rubella is truly an international concern. And because the community of service providers in each country is so small, we need to stay in touch, continue to share information, and work towards worldwide immunization while addressing the service needs and health concerns of those living with CRS. There are many countries with far fewer resources than ours, yet their attitudes and energy levels are incredible. Many wonderful connections were established during the symposium that we want to continue. The first thing the group decided to do was to establish a Listserv for professionals. That was quickly accomplished, and it has become a great place to brainstorm about medical questions, training opportunities, and general support. We also decided to apply to become a network through DbI (Deafblind International). The application has been submitted, and we are awaiting a response. The network would allow us to have meetings in conjunction with DbI's international meetings, post information on their Web site, and encourage full international participation. We hope to have our first "official" meeting as a rubella network at the 2007 DbI conference in Australia. We are also working on putting together a database of professionals who are willing to be resources for parents or service providers and hope to welcome additional medical personnel into the fold. In the meantime, we will be working to compile the proceedings from the symposium. Check the HKNC website (<http://www.hknc.org>) for more information.

On a final note, in 2004 HKNC conducted a survey of individuals with CRS to collect information about the population including communication styles, living and employment situations, and late manifestations. Although analysis of the results was put on hold to plan for the symposium, we have now hired a statistician to analyze the results. We will keep you posted.

The symposium was an awesome experience that could not have been pulled off without the participation and cooperation of many people around the world. We owe them our thanks. Although rubella has been eradicated in the U.S., CRS continues to affect thousands of Americans. There is still much work to be done.

References

CDC (Centers for Disease Control and Prevention). (2005). Achievements in public health: Elimination of rubella and congenital rubella syndrome—United States, 1969–2004. *Morbidity and Mortality Weekly Reports*, 54(11), 279–282. Accessed August 21, 2005, at <http://www.cdc.gov/mmwr/PDF/wk/mm5411.pdf>.

Menser, M. A., Dorman, D. C., Kenrick, K. G., Purvis-Smith, S. G., Slinn, R. F., Dods, L., & Harley, J. D. (1969). Congenital rubella: Long-term follow-up study. *American Journal of Diseases of Children*, 118(1), 32–34.

McIntosh, D. E., & Menser, M. A. (1992). A fifty-year follow-up of congenital rubella, *The Lancet*, 340(8816), 414–415.

WHO (World Health Organization). (2000). Rubella vaccines: WHO position paper. *Weekly Epidemiological Record*, 75, 161–169. Accessed August 21, 2005, at <http://www.who.int/wer/pdf/2000/wer7520.pdf>



Personal Perspectives

Selecting the Right Assistive Technology for Me An Ongoing Journey of Self-Reflection and Empowerment

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Kansas Project for Children and Young Adults Who Are Deaf-Blind

Thanks to advances in computer and communications technologies, society is able to share information and communicate interactively at increasingly astonishing rates. It seems as if many people in the world today just can't get enough of the latest gizmos and gadgets, including state-of-the-art assistive technology devices. As a profoundly deaf-blind adult, I have a strong yearning for anything that will help improve my opportunities to share information and interact with others in ways that mirror the capabilities of my hearing and sighted peers. At the same time, I have learned from experience that it is best to resist the temptation to find a quick fix when it comes to assistive technology (AT) devices and to seek the help of family, professionals, and service providers to fully research which devices will best serve my goals for daily living, social interaction, education, and employment.

Even before I entered the field of deaf-blindness professionally, people would frequently ask what worked for me with the hope of gaining insight into how AT devices might aid their interactions with a particular deaf-blind family member, friend, or student. While I can and usually do share openly what I have found to work for me personally, I also stress that what works for me in

my unique situation may or may not match the specific needs of another deaf-blind person.

Assistive technology devices often require considerable financial and emotional investment by the user to acquire, learn to use, and maintain. Thus it is essential to be well-informed when making a decision about whether a device will meet the unique needs of a specific deaf-blind person. Important factors to consider include the level of productivity that the device will provide, its adaptability, and the degree to which expectations of the deaf-blind person, family, and service providers about the device are realistic.

Efficiency and Productivity

When considering the efficiency or productivity that a given AT device enables, I ask myself, "How will this particular device be of help to me right now in my current situation?" I must be clear about what I want and realistic about what the device can and cannot do to meet my current needs. Many devices on the market can do amazing things, but whether they can be of specific help to me right now is what I really want to know.

The effectiveness of a device also depends on how well the deaf-blind person is able to use it. For every device there is a learning curve. For example, I needed to learn a new skill to use a device as simple as a monocular to locate street signs. Because I have only 3 degrees total peripheral vision in my left eye, simply looking through the magnified end of a monocular wasn't much help. My orientation and mobility instructor showed me that, by turning the monocular around and looking through the opposite end, I could locate a street sign in the larger visual field. By turning it back around to the magnified end, I could then find the top of the pole to read the sign. To get full use of the monocular, I had to learn the technique and practice it. Fortunately, I am a patient and willing learner.

It is also helpful to think about how long a particular device will be of benefit to the deaf-blind individual. It is often very difficult, if not impossible, for even the best experts to determine how and when a person's needs may change, but this is a factor that should be kept in mind. My vision has decreased significantly over the past five years, and some AT devices that once worked for me are no longer useful. For example, when my visual field was larger than it is now, I used a closed circuit television (CCTV). The magnification, the ability to change background and print colors, and the orientation line on the screen all

helped me significantly when I could actually see more. But after three years, as my vision decreased, I had to move on to becoming a much more proficient Braille reader.

Adaptability

Very few assistive technology devices were developed with the specific needs of deaf-blind people in mind. Therefore, it is unlikely that a particular device will match all the accessibility needs of a given deaf-blind person "right out of the box." It is important to consider how a device can be adapted to meet the needs and desires of a specific person. Some devices can be adapted relatively easily without a lot of expense, time, and effort, while others require considerable assistance from a collaborative team of family members, professionals, school staff, and other service providers.

Realistic Expectations

While many of the available AT devices today are simply awesome, it is important to keep in mind that no device in and of itself is "magic." I have a Clarion HiFocus cochlear implant in my left ear. I was able to hear my youngest son say "Daddy I love you!" for the very first time as soon as it was activated on my 46th birthday (he was 15 ½ years old at the time), but I am still very much a deaf-blind person. I had been severely hearing impaired all my life and profoundly deaf for over 14 years before getting my cochlear implant. The AT involved with the implant worked right away, but I still needed almost a year of regular auditory and speech training to be able to get the most benefit and to allow for the development of auditory processing and for my brain to "catch up." Even though I met and exceeded my personal expectations of being able to monitor my own voice and to gain improved environmental auditory input for orientation and mobility and even though I can now, after four years, converse with my wife, close friends, and very familiar colleagues on a voice telephone, I am still a profoundly deaf-blind adult. The implant doesn't help much when there is loud background noise because then I cannot tell where environmental sounds I hear are coming from or how far away they might be. When the implant's batteries run out (sometimes at the most inopportune times), I am actually more profoundly deaf than I was before my cochlear implant surgery and activation. So again, it is very important to be very realistic and honest about what a given AT device may provide.

Also, there may be an emotional impact when uncontrollable changes in vision, hearing, and other accessibility needs dictate the need for a new device, as for example, in my case when it was necessary to introduce new methods of acquiring print and electronic information via Braille reading. It doesn't matter if the device is high tech or low tech. Even initial acceptance and use of some low-tech AT devices can be very difficult emotionally for a person experiencing any level of deaf-blindness. I was deaf-blind for quite a while before I was emotionally ready to use a white cane for my orientation and mobility needs. While a four-piece graphite white cane is typically sold at a modestly affordable price, the facts of my being a late-deafened adult and a school psychologist on a residential deaf school campus combined to make the cane's use a real emotional milestone for me.

Conclusion

The person-centered focus that I use to research and select AT devices has quite often proven to be as personally beneficial as the devices themselves have been. Although the process is not always easy or comfortable, the emphasis on my unique needs and situation can result in a thoughtful and reflective journey that engages, enables, and empowers me as a deaf-blind person. In so doing, the chances of choosing just the right AT device have significantly improved for me.

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Educational Guidelines Underway

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DB-LINK**

In June, the Hilton/Perkins Program, in conjunction with the National Association of State Directors of Special Education (NASDSE), hosted a meeting in Boston to begin discussion on the development of educational service guidelines for students who are deaf-blind. The format for the guidelines will be modeled after *Blind and Visually Impaired Students: Educational Service Guidelines*, published by NASDE in 1999. These guidelines

were also developed in cooperation with Hilton/Perkins and have been used to provide training seminars for special education personnel in more than 28 states.

The group included representatives from state and multistate deaf-blind projects, university training programs, educational programs serving students who are deaf-blind, NTAC, and DB-LINK. Gaylen Pugh from NASDSE opened the meeting with an explanation of the history and development of the guidelines that were developed for blind and visually impaired students, their importance as a foundation for training, and most importantly, their impact on service delivery. Her presentation provided an excellent foundation for the development and use of the guidelines for students who are deaf-blind.

Over the two-day session, the group worked to develop an outline that would reflect quality educational services for children who are deaf-blind. Issues were organized around five main sections: foundations for educating students with deaf-blindness, supportive structure and administration, assessment, program requirements and placement options, and personnel.

A first draft of key sections is planned for late September. The Project Director's meeting in Washington, DC, in October will provide an opportunity to solicit input from state deaf-blind project staff and to discuss guidelines dissemination and training components. The projected time line for the finished document is 18 to 24 months. Marianne Riggio is the lead person for this project, and she can be reached at 617-972-7264 or Marianne.Riggio@Perkins.org.



Research Update

The "Struggle to Symbolism" Studies

**Submitted by
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While all children communicate, not all acquire language. Most children who are congenitally deafblind are severely delayed in communication development, and many do not make the transition from intentional presymbolic communication to symbolic language (Mar & Sall, 1994; Siegel-Causey & Downing, 1987). Symbolic expression involves

the use of symbols such as words or objects to represent concepts or things and makes possible communication about someone or something that is not in the current environment and about events that occurred at another time. The ability to express oneself symbolically is necessary for the development of language, which allows one to express thoughts more fully and accelerates cognitive development.

The goal of the Struggle to Symbolism Project's studies is to capture detailed information about the communication of children with severe disabilities who are intentional communicators but have not yet acquired language. This data will support the development of educational models to help deafblind children develop communication skills and language. The studies included 17 children, aged 3 to 10 years, with severe developmental delay (7 are deafblind, 7 are nonambulatory, and 3 have pervasive developmental disorders). All of the children were observed and videotaped during classroom activities, and about one-third were also filmed at home.

Assessment tools were used to gather additional information. Teachers and parents completed the Play Assessment Questionnaire (Yoshinaga-Itano, Snyder, & Day, 1999), which provides information about a child's level of play, differences in play across settings, and the level of symbolism the child uses while playing. Each child was also assessed using the Communication Matrix (Rowland, 1996).

Using the information gathered from the videotape data and the assessments, detailed communication profiles were developed for each child and provided to their instructional teams. The profiles displayed information on each child's expressive and receptive forms of communication, level of mental representation (ranging from symbols or pictures that look very much like what they represent to abstract symbols), intents and functions expressed (such as request and protest), optimal rate of communication in the school setting, words initiated and imitated, sharing of affective states, gaze shift (between two objects and between an object and a person), level of joint attention (sharing of attention between two people), evidence of memory, evidence of specific cognitive milestones (such as object permanence and cause-and-effect), use of repair strategies (such as rephrasing), and level of play. The profile information was then used to suggest communication interventions appropriate for each study child.

The Struggle to Symbolism studies began with an extensive review of the literature on presymbolic and early symbolic communication. The items in

the profiles were selected because each had been cited by researchers as being important to the development of symbolic expression in both children with typical development and children with disabilities. The research findings and detailed profiles produced by this project will add to the research literature on the communication development of children who are congenitally deafblind, while also providing instructional teams with information that could result in program change. The results will hopefully lead to additional research that includes larger samples of children who are congenitally deafblind.

A few findings from a review of the profiles and play assessments of the children who are deafblind are shared here. There is evidence that some functions (or purposes) of communication are achieved before others and that a variety of functions can be expressed prior to acquiring language. All of the children in this project expressed the functions of giving object, showing object, accepting object, protest, requests of various types, and calling attention when a desired person is nearby. The profiles revealed few examples of children expressing labels (names for people and objects), comments, or initiating greetings. A combination of teacher, parental, and peer modeling of early functions and the creation of opportunities for the child to express such functions can help an individual child to communicate an increased number of functions.

There were some interesting patterns in play assessment as well. Even though the children were at different levels of play development, they all struggled with certain elements of play, such as grouping and organizing toys or objects for a play routine. This was true for even the children who demonstrated far more advanced play skills. Such a finding could indicate the need to increase opportunities for the child to participate in gathering items that will be used in play or other activities.

The following section details the status of various project studies and articles included in the Struggle to Symbolism Project. We are currently coding the gestures expressed by study children and identifying the contexts that evoked the highest rates of intentional communication acts. Analysis of the play assessment results continues. The following articles (based on the review of the literature for these studies) have been recently published:

- ◆ Bruce, S. (2005). The application of Werner and Kaplan's "distancing" to children who are deaf-blind. *Journal of Visual Impairment & Blindness*, 99(8), 464-477.

- ◆ Bruce, S. (2005). The impact of congenital deafblindness on the struggle to symbolism. *International Journal of Disability, Development and Education*, 52(3), 233-251.

The following articles and studies are currently in progress:

- ◆ Bruce, S., & O'Donnell, K. (in review). Colby's daily journal: The power of a coordinated teacher-parent effort on communication development. (This article features a video clip of a child who is congenitally deafblind.)
- ◆ Bruce, S., Fasy, C., Gulick, J. Jones, J., & Pike, L. Making morning circle meaningful. (This article includes video clips of children who are congenitally deafblind.)
- ◆ Bruce, S., & Vargas, C. Classroom contexts that support high rates of intentional communication acts (ICAs).
- ◆ Bruce, S., Mann, A., Layton, K., & Jones, C. The function of gestures in children who are congenitally deafblind.
- ◆ Bruce, S., & Fasy, C. The play of children with multiple disabilities.

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References

- Mar, H., & Sall, N. (1994). Programmatic approach to use of technology in communication instruction for children with dual sensory impairments. *AAC Augmentative and Alternative Communication*, 10(3), 138-150.
- Rowland, C. (1996). *Communication Matrix*. Portland, OR: Design to Learn.
- Siegel-Causey, E., & Downing, J. (1987). Nonsymbolic communication development: Theoretical concepts and educational strategies. In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments* (pp. 15-48). Baltimore: Paul H. Brookes Publishing Co.
- Yoshinaga-Itano, C., Snyder, L., & Day, D. (1999). The relationship of language and symbolic play in children with hearing loss. *Volta Review*, 100(3), 135-164.

New Research Project

Outcomes for Children Who Are Deaf-Blind after Cochlear Implantation

Teaching Research Institute at Western Oregon University was recently awarded a grant from the U.S. Department of Education to study the outcomes of cochlear implantation for children who are deaf-blind. The grant is funded under the Department's Steppingstones of Technology Innovation for Students with Disabilities program. The three-year research project will be carried out in collaboration with the University of Kansas, the Midwest Ear Institute/St. Luke's Hospital, and approximately ten state deaf-blind projects including CA, KS, NE, NJ, NY, OR, PA, TX. The objectives include the following:

- ◆ Compile demographic information on children who are deaf-blind who receive cochlear implants.
- ◆ Identify a protocol of assessments to measure changes in auditory perception, language acquisition, communication, social interaction skills, and functional life skills.
- ◆ Develop a protocol to address four research questions: (a) Which children between the ages of 12 months to 12 years receive cochlear implants? (b) How does a cochlear implant impact auditory perception, social skills, communication, and language development? (c) How do age of implantation, severity of visual impairment, cognitive level, presence of additional disabilities, and length of time since implant impact outcomes of cochlear implantation? (d) To what degree do the intensity, duration, and quality of post-implantation habilitation services contribute to the positive or negative progress of a child who has received a cochlear implant?

For more information contact: Dr. Ella Taylor, Project Director, Teaching Research Institute, 345 N. Monmouth Ave., Monmouth, OR 97361. Phone: 503-838-8589. E-mail: taylor@wou.edu.

National Center for Special Education Research (NCSEER)

The U.S. Department of Education's National Center for Special Education Research (NCSEER), one of four centers within the Institute of Education Sciences, supports a comprehensive research

program to promote research on special education and related services, and to address the full range of issues facing children with disabilities, parents of children with disabilities, school personnel, and others. The Individuals with Disabilities Education Improvement Act of 2004 transferred the responsibilities for research in special education within the U.S. Department of Education from the Office of Special Education and Rehabilitative Services to the Institute of Education Sciences. Information on the FY 2006 special education research competitions is available on the Institute's funding page: <http://www.ed.gov/about/offices/list/ies/programs.html>.

If you have information that you would like to include in "Research Update," contact:

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For Your Library



Autism Spectrum Disorders and Visual Impairment: Meeting Students' Learning Needs

Marilyn H. Gense and D. Jay Gense. New York: AFB Press, 2005.

This book offers a comprehensive look at how autism interacts with vision loss and presents effective ways to work with students. Cost: \$49.95. Available from AFB Press. Phone: 800-232-3044. E-mail: afbpress@afb.net Web: <http://www.afb.org>.

Interpreting Strategies for Deaf-Blind Students: An Interactive Training Tool for Educational Interpreters [DVD & Manual]

Susanne Morgan, Ohio Center for Deafblind Education, University of Dayton. 104 pages [DVD 60 minutes]

This curriculum is designed to train interpreters to work with students who are deaf-blind. It consists of a 60-minute narrated DVD and a print manual. There are 8 modules covering legal issues related to interpreting and deaf-blind education, interpreting methods (sign language, voicing using an

FM system, typing, braille), environmental and sign language modifications, and strategies to help interpreters work effectively with teachers and students to make sure that deaf-blind students have access to educational content and the classroom environment. Each module includes a self-check quiz. The DVD provides numerous examples of the content covered by the manual and additional opportunities for self-testing. Cost: \$15.00. Copies may be ordered from the Ohio Center for Deafblind Education (OCDBE), 4795 Evanswood Drive, Suite 300, Columbus, OH 43229. Phone: 614-785-1163. E-mail: ocdbe@sco.org.

A Study of Deaf-Blind Demographics and Services in Canada: A Report Prepared for the Canadian National Society of the Deaf-Blind

Colleen Watters, Michelle Owen, & Stan Munroe. Canadian National Society of the Deaf-Blind, 2004

This is a very detailed report of a study of deaf-blind people in Canada. In addition to extensive demographic data, it contains information about the every day lives, feelings, experiences, and service needs of deaf-blind individuals and their parents and advocates. Available in electronic format. There is a link to the full report on the publisher's Web site: <http://www.cnsdb.ca>.



Find information about...IDEA
(Individuals with Disabilities
Education Improvement Act of
2004)

In the Selected Topics section of
the DB-LINK Web site.

One of the easiest ways to locate current, well-organized information on nearly 60 pertinent subjects is to hitch a ride from the Selected Topics section of the DB-LINK Web site: <http://www.dblink.org>. This month we invite you to look at what we currently have organized under IDEA. Here you will find links to the new law and proposed regulations, the Office of Special Education Program's topical information sheets, the Council for Exceptional Children's side-by-side analysis of IDEA 1997 and IDEA 2004, and links to current information and news.

Conferences and Events

Getting In Touch With Literacy Conference December 1-4, 2005 Denver, Colorado

This is a national conference focusing on the literacy needs of individuals with visual impairments (including deafblindness). The theme is "Living Literacy." For more information contact Kay Ferrell, National Center on Low-Incidence Disabilities, University of Northern Colorado. Phone: 970-351-1653. E-mail: kay.ferrell@unco.edu. Register online at <http://www.gettingintouchwithliteracy.org>.

Deafblind International Asia Conference January 29-31, 2006 Dhaka, Bangladesh

The theme of DbI's second Asia Conference is "Deafblindness—Breaking Barriers in Asia." Web: <http://www.deafblindinternational.org>.

American Association of the Deaf-Blind National Conference June 17-23, 2006 Baltimore, Maryland

The next conference will be held on the campus of Towson University in Baltimore. Watch for details on AADB's Web site and in *The Deaf-Blind American*. For more information contact AADB. Phone: 301-495-4403. TTY: 301-495-4402. Email: info@aadb.org. Web: <http://www.aadb.org>.

Deafblind International 14th World Conference September 25-30, 2007 Perth, Western Australia

The conference will be hosted by Senses Foundation. The theme is "Worldwide Connections: Breaking the Isolation" and its goal is to make progress toward breaking the isolation that people with deafblindness experience by breaking down barriers and building worldwide connections and networks amongst countries and organizations. For information see <http://www.senses.asn.au>.

Web-Based Seminar on Core Curriculum Access Online

NTAC and the Access Center, in collaboration with the LRE Part B Community of Practice, recently sponsored a Webinar called *Making Abstract Core Curriculum Accessible to Students with Severe and Multiple Disabilities*. A Webinar is a seminar that is presented on the Web. The presenter, Dr. June Downing from the California State University, Northridge, identified ways to make even abstract core curriculum relevant and meaningful to students with significant and multiple impairments. Samples of adaptations were used to highlight points made across K-8 curriculum. This course and past Webinars are available for viewing and listening on the Access Center's Web site: http://www.k8accesscenter.org/online_community_area/Webinar.asp.

Helen Keller National Center National Training Team Seminars 2006 Sands Point, NY	
January 23-27, 2006	Employment: The Ultimate Goal - Professional Development for Employment Training Specialists
April 3-7, 2006	Communication Options for Persons Aging with Hearing & Vision Loss
May 1-5, 2006	Community Integration for Persons Aging with Hearing & Vision Loss
May 21-26, 2006	Orientation & Mobility Techniques for Deaf-Blind Travelers: Same but Different
July 24-28, 2006	Addressing Psychosocial Issues Faced by Persons Aging with Hearing & Vision Loss
August 7-11, 2006	Interpreting Techniques for the Deaf-Blind Population: Touching Lives
September 11-15, 2006	Enhancing Services for Older Adults with Vision & Hearing Loss: The Best is Yet to Come
September 25-29, 2006	Disability Rehabilitation/Research Project Persons Aging with Hearing & Vision Loss (On-line Seminar)
October 23-27, 2006	Person-Centered Approach to Habilitation: Transformation
November 13-17, 2006	Technology Seminar: The Magic of Technology
Contact HKNC: Phone: 516-944-8900, Ext. 233. TTY: 516-944-8637. E-mail: ntthknc@aol.com . Web: http://hknc.org/FieldServicesNTTSchedule.htm	

Deaf-Blind Perspectives

Paper copies of *Deaf-Blind Perspectives* are available free of charge to subscribers within the United States. E-mail subscriptions (provide notification that a new issue has been placed online) are available for International subscribers and others who prefer the online format.

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

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Fax: (503) 838-8150, E-mail: dbp@wou.edu 1005

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