

# Deaf-Blind Perspectives

Volume 7, Issue 3

Spring 2000

## Lessons from Project PLAI in California and Utah: Implications for Early Intervention Services to Infants who are Deaf-Blind and Their Families

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**A**ppropriate early intervention services are important for the development of communication skills in infants who are deaf-blind. Oftentimes, however, early intervention programs are not staffed by people knowledgeable about the specialized needs of infants who have both visual impairment and hearing loss. One of the goals of a recent project called Project PLAI (Promoting Learning Through Active Interaction), was to develop resource materials that early intervention programs could use to teach families how to promote their infants' communication development. Early intervention programs provide services for children from birth to age three. The teachers and other service providers who work with children in these programs are called early interventionists.

Project PLAI was a research-to-practice project funded by the U.S. Department of Education Services for Children with Deaf-Blindness. It involved faculty at California State University, Northridge and California State University, Los Angeles working together with the SKI-HI Institute at Utah State University and early intervention programs in both states. Project PLAI developed an early communication curriculum (Klein, Chen, & Haney, in press) and accompanying videotape (Chen, Klein, and Haney, in press). The project then evaluated these materials while training early interventionists to use the curriculum with families and their infants who are deaf-blind. The curriculum contains five sections with strategies for recognizing communication behaviors, responding to them, and thus supporting early communication development. (An outline of the modules accompanied by a case study demonstrating their use follows this article).

In a 1995 article, Chen & Haney described the underlying principles of the PLAI model. In the final report (1999), they documented the validation process, widespread training activities, and the project's many outcomes. This article describes how the project was implemented in southern California and Utah. It notes the extensive challenges to effective early intervention services and presents ideas for improving them.

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### Diversity of Project Participants

The field-test group consisted of 25 infants, their caregivers, and early interventionists in southern California and Utah—those who completed all project activities. (Seven other infants and families began the project but were unable to continue because of the infant's medical needs or family situations.)

**Infants.** All infants had significant and multiple disabilities in addition to visual impairment and hearing loss. Half had gastrostomy tubes (a type of feeding tube), and a similar number had seizures. One-third were on respirators, a quarter had tracheostomies (an opening into the trachea through the neck into which a breathing tube is inserted), and most had been hospitalized at least once since birth. One third of the infants had hearing aids and

some had glasses, but few of them wore their hearing aids or glasses consistently.

Cortical visual impairment was the most common cause of vision loss, occurring in two-thirds of the infants. Other visual problems included refractive errors, retinal problems, coloboma, microphthalmia, and other congenital ocular anomalies. A quarter of the infants had no functional vision. More than a third did not respond to sound consistently. Half had slight-to-mild hearing losses, a quarter had moderate losses, and a quarter had severe or profound losses. All of the infants had moderate-to-profound developmental delays, and half had physical disabilities.

The infants were between 8 and 33 months old (mean 19.8 months) when they began the curriculum and between 14 and 50 months (mean 31.6 months) when they completed it. Families took between 6 and 21 months to complete the curriculum (average 13.8 months). A quarter completed it in 6 to 8 months. Others needed more time because of their infants' medical needs, hospitalization, family situations, and other factors such as early interventionist's schedules and priorities, and winter weather in Utah that sometimes made travel difficult.

**Caregivers.** The primary caregivers participating in the project were the children's mothers (including a foster mother and a grandmother). Several fathers were also involved in project activities. These 25

families represented a variety of educational, socioeconomic, and linguistic backgrounds. Two parents had just two years of school, most were high school graduates, some had college degrees, and two had doctoral degrees. Their cultural backgrounds included African-American, Euro-American, and Hispanic. Some Hispanic families were bilingual, and others spoke only Spanish.

**Early Interventionists.** In southern California, participating programs involved two private agencies and three local educational districts. In Utah, the families received services from the Deaf-Blind Services Division of the Utah Schools for the Deaf and the Blind. Some early interventionists worked with more than one family participating in the project and some families had more than one early interventionist working with them.

Sixteen early interventionists completed the curriculum with their families. They had a variety of qualifications: One was a paraprofessional (high school graduate and parent of a child with a disability); two had credentials and master's degrees in the area of deaf and hard of hearing; one had a credential in the area of visual impairments; one had a credential in the area of deaf-blindness and a master's degree; five had bachelor's degrees in child development or related fields and inservice training in early intervention; and two had master's degrees in special education (one in orientation and mobility and the other in severe disabilities) but minimal back-

### *Deaf-Blind Perspectives*

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ground in early intervention. Two were completing their master's degrees and credentials in early childhood special education, and two others were working on a credential in early intervention competencies.

The families and the early interventionists participated in an annual focus group meeting (held in Northridge and Salt Lake City) to evaluate the curriculum process and project activities. Their feedback was invaluable. It guided project procedures and supplemented evaluation data collected from videotaped observations, interviews, and recording sheets. The usefulness of the curriculum was thus validated in spite of the diversity of the families and infants and the diversity of qualifications of the early interventionists.

### Training The Early Interventionists

The project trained early interventionists to use the curriculum with caregivers during their regular weekly or monthly home visits with the infant. (Factors such as illness or hospitalization of the infant, family situations, other appointments, IFSP meetings, or weather conditions sometimes caused this schedule to vary.) Videotape segments of the infant and caregiver during selected activities and interview information about the infant's communication were used during the training. These same materials were then used by the early interventionists to teach caregivers to use the curriculum strategies. Before training, most of the early interventionists in southern California were not familiar with the key concepts of the curriculum, with strategies for working with infants who are deaf-blind, or with teaching techniques and data collection. At first, some had difficulty integrating the PLAI strategies into their typical home visit activities. They also needed assistance explaining the strategies to caregivers. Many were not yet proficient interviewing or coaching families, or in maintaining contact to complete an objective if a home visit was cancelled. However, once early interventionists and families became familiar with the curriculum, it became easier to use, and the modules were completed more quickly.

In California, early interventionists received training on the curriculum at California State University, Northridge (4 half-day or 2 all-day sessions), with time between each session to use specific modules with the families. They then received follow-up support from one of two part-time project coordinators (one was bilingual in Spanish and English) who discussed parts of the curriculum that had been covered during training, provided examples of how particular objectives might be taught, demonstrated

how to explain concepts to caregivers, and showed how to complete the data collection sheets. The coordinators also collected baseline and ongoing data through interviews and videotaped observations during home visits with the family.

In Utah, two all-day training sessions (with time to use specific modules between each session) was provided for three deaf-blind consultants who already had significant inservice training and experience in early intervention and deaf-blindness. They were already skilled in explaining learning activities to caregivers and interveners (paraprofessionals who worked with the child at home) and were familiar with most of the strategies in the early modules of the curriculum. These consultants learned new strategies from PLAI, including use of a behavioral analysis of infant responses by identifying antecedent events and consequences, turn-taking routines, interruption and delay strategies, and data collection. They required some support from the project in completing data collection sheets. The project coordinator at the SKI-HI Institute collected baseline and ongoing data through interviews and videotaped observations.

### Challenges for Early Intervention Services

**Limited Numbers of Trained Interventionists.** A major challenge in southern California is a lack of early interventionists trained to work with infants who are deaf-blind. Under Part C services in California, infants with visual impairment, hearing loss, and deaf-blindness with no additional disabilities, are served by school districts. Disabled infants who have other low incidence disabilities (including cognitive delays and multiple disabilities including visual impairment and/or hearing loss) usually receive services from early intervention programs at private agencies. These are contracted by regional centers funded through the Department of Developmental Services. However, school districts continue to serve infants with a range of disabilities if they did so before 1986 when the passage of P.L. 99-457 provided a federal incentive for states to address the needs of infants and toddlers with disabilities and their families. Thus some infants in the project received services from private early intervention programs and others from public schools. Early interventionists in school district programs have a variety of credentials in special education although it is likely that few have received preservice or comprehensive inservice training in working with infants with severe and multiple disabilities or who are deaf-blind. Service providers in private agencies

may be even less qualified since the Department of Developmental Services has not implemented early intervention personnel standards.

In Utah, early interventionists called "deaf-blind consultants" (from the Utah School for the Deaf and the Blind) and interveners provide early intervention services. Intervenors provide direct services to the child approximately 10 hours a week and the consultants provide parent education and support during bimonthly home visits. Intervenors receive state-sponsored intervener training from the SKI-HI Institute and the Utah School for the Deaf and the Blind. Deaf-blind consultants have bachelor's or master's degrees in special education with inservice training in deafblindness through an 82-hour intervener training course and ongoing professional development opportunities. Utah does not have certification in the area of deaf-blindness, but has developed personnel competencies in deaf-blindness early intervention.

In Utah, infants who are deaf-blind may also receive services from general early intervention programs for physical or occupational therapy, service coordination, speech and language therapy, and nursing. They also receive services from the Parent Infant Program at the Utah School for the Deaf and the Blind, whose teachers are certified in visual impairments or in the deaf and hard of hearing area.

**Lack of Early Identification and Follow-Up.** Another challenge to providing early intervention services in both California and Utah is the lack of early reliable identification of visual impairment and hearing loss, especially when infants have multiple disabilities. Sometimes this occurs because other medical survival needs are considered to be more important. In other cases, visual impairment may be diagnosed but the infant's hearing status is unknown. This year, California has begun universal infant hearing screening in about 200 hospitals that are approved by California Children Services and in others that have neonatal intensive care units. However, coordination of screenings, follow-up, and early intervention services still needs to be developed.

Universal hearing screening for infants in Utah began in 1993, but was not mandated until 1998 and not fully implemented until July 1999. Hospitals refer infants who have failed screening to a state or local early intervention agency, the school for the deaf or the school for the blind, or to the infant's physician for diagnostic evaluation. The health department coordinates follow-up and referrals to early intervention services when necessary.

In southern California, several families involved in Project PLAI, particularly those who do not speak English, did not know how to obtain vision and hearing evaluations for their infants. In both California and Utah, when infants were diagnosed as having a visual impairment and hearing loss plus other significant disabilities, few received glasses or hearing aids when appropriate. Most of those who did have glasses or hearing aids did not wear them consistently. We believe this lack of follow-up was influenced by the infants' medical needs and disabilities and by the priorities of families and early intervention programs. Additionally, some audiologists and ophthalmologists may not prescribe glasses or hearing aids if the infant has intensive medical needs and significant developmental delays. Further, insurance or financial difficulties prevented some families from obtaining hearing aids or glasses that were prescribed for their infants, and some early intervention programs failed to provide follow-up support in this area.

## Implications for Improving Early Intervention Services

Our experience in Project PLAI has identified essential aspects of providing appropriate early intervention services to infants who are deaf-blind and their families. First, the shortage of qualified personnel serving these infants and families requires organized preservice and inservice training efforts to increase professional competencies not only in specialized skills related to the infant's multiple disabilities and sensory impairments, but also in general skills. These include (a) working with families of diverse backgrounds, (b) coaching families in communication strategies with their infants, (c) encouraging the use of hearing aids and glasses when prescribed, (d) weaving intervention strategies into the family's routine, (e) collecting data, and (f) participating as a member of an interdisciplinary team. The multiple learning needs of infants who are deaf-blind require qualified professionals who can help families obtain appropriate medical treatments, hearing and vision evaluations, and other related services.

Second, the complexity of these infants' learning needs demands a team approach. Service providers need to meet with each other and with families in order to plan how to best meet the infant's needs and the family's concerns.

Third, families receiving services through home visits need regular contacts with other families and service providers. Although the home is a "natural environment," many parents in the project felt iso-



lated and indicated that they appreciated the annual focus group meetings. Most of these parents wanted additional opportunities for contact with other families who had children with similar learning needs.

Further, Spanish-speaking families participated more actively in groups with others who spoke their language than in those where they had to rely on communication through interpreters. The large Spanish-speaking population in southern California requires the recruitment and training of bilingual early interventionists, development of appropriate materials for Spanish-speaking families, and opportunities for these families to meet each other.

### Summary

Providing early intervention services to infants who are deaf-blind and their families is complicated. Not only do the age, abilities, and needs of each infant require an individualized approach, but also family priorities, home culture and language, location, program resources, and state policies influence the nature of intervention services. These complexities emphasize the need for state technical assistance projects and other state agencies to work together to provide professional development activities for service providers and educational and networking opportunities for families of infants who are deaf-blind.

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Project PLAI was supported, in part, by the U.S. Department of Education Research to Practice Grant #HO2554001 to California State University, Northridge; however, the content of this article does not necessarily reflect the position of the U.S. Department of Education, and no official endorsement should be inferred.

## Research-to Practice: PLAI Curriculum Modules and Case Study

The PLAI curriculum modules are listed below, followed by examples of how each was used with a 14-month old child named Michael. The examples follow Michael, his mother, Cecelia, and his older sister, Kate, as they go through the five modules. Michael was born very prematurely at 26 weeks gestation. He weighed 1 pound, 8 ounces. At the time he was discharged from the hospital, he had been diagnosed with multiple disabilities, including severe retinopathy of prematurity, spastic cerebral palsy, and an undetermined degree of hearing loss. During his first year, his development was very slow. He was often irritable and feeding was difficult. Cecelia was very concerned and wanted to promote Michael's interest in communicating and playing.

### Module 1: Understanding Child Cues

**Goal:** Caregivers will develop a detailed picture of the ways in which the child expresses attention and interest, pleasure and discomfort, and needs and desires.

#### Caregiver Objectives:

- ◆ Complete a Typical Daily Activities Form describing the child's typical day.
- ◆ Learn to identify the child's state of arousal.
- ◆ Through careful observation of antecedent events and consequences, develop a clear understanding of the child's typical reactions during familiar routine activities.
- ◆ Identify and describe ways in which the child obtains the attention of the caregiver and for what purposes.
- ◆ Describe how the child reacts to and expresses external states/feelings.

Describing a "typical day" was challenging. Cecelia's schedule was fairly unpredictable. She would sometimes help out in her uncle's bakery when they were shorthanded, usually in the late afternoon or evening when Kate could stay with Michael. And she would often baby-sit her sister's children. The most predictable events occurred early in the morning and late at night. The family got up at about 6 a.m. Cecelia would fix Kate's breakfast

and give Michael his bottle. After Kate left for school, Cecelia would give Michael a bath and dress him. For the rest of the day, the schedule was unpredictable until nighttime. Kate or Cecelia gave Michael his bottle. Sometimes Kate rocked him to sleep while watching TV.

When asked to think about Michael's reactions, states, and feelings, Cecelia thought about how Michael expressed pleasure and interest. He extended his arms and legs slightly, moved his head downward, and then became very still. She also recognized that Michael became upset *before* he actually started to cry—he would pull his head up, extend his legs, and clench his fists. As Cecelia observed Michael's reactions to familiar daily activities, she learned that when she went to lift him from the crib, he would automatically extend his arms and legs. She wondered how he could sense her presence, and at first thought maybe it was her imagination. But after several observations she realized that his response was consistent. He would always respond as she approached the crib.

After this discovery, Cecelia and Kate sought to discover other things they hadn't known about Michael. When he was drowsy or "tuned out," his head was turned to the side and slightly down. When he was alert and attentive, his head would move toward midline, though still down, and he would extend his arms and legs. When his head was up, he was actually becoming upset and over-aroused. Cecelia also discovered that when she took hold of Michael's hands and massaged his fingers (which she had always assumed he liked) his head would come up and his fist would clench slightly. But when she massaged his shoulders and upper back, his fists would relax and his head would turn to midline and down.

## Module II: Identifying High and Low Preference Objects, Persons, and Events

**Goal:** Caregivers will develop a thorough understanding of what their child enjoys and dislikes.

### Caregiver Objectives:

- ◆ Generate a detailed list of activities, persons, and objects that they believe the child enjoys and those the child dislikes.
- ◆ Describe child's reaction to the presentation and removal of specific objects, persons, and sensory events.

After the period of observing and learning more about Michael's cues, Cecelia and Kate could more easily identify Michael's preferences and aversions. His favorite things were his mom, cinnamon rolls, shoulder massages, and rocking in Kate's lap. He hated citrus fruits, being naked, and being immersed in water. He also didn't like having his hands touched or sudden loud noises.

Kate was particularly enthusiastic about this new project. She discovered that Michael had a good sense of smell; that he loved certain smells and hated others. His favorite seemed to be the smell of cinnamon rolls that Cecelia would bring home from the bakery. Kate could even get Michael to stop fussing by putting the cinnamon roll under his nose, then giving him a little taste. She also learned that when Michael smelled fruits like oranges or lemons, he would throw his head back and cry.

## Module III: Establishing Predictable Routines

**Goal:** Caregivers will create a daily routine that includes several predictable events that the child can anticipate through recognition of certain cues (words, sights, or other sensations).

### Caregiver Objectives:

- ◆ Create a predictable routine by identifying at least five daily activities that can be scheduled in the same sequence each day.
- ◆ Identify predictable sequences within specific activities (i.e., "subroutines").
- ◆ Identify and use specific auditory, visual, tactile, olfactory, and kinesthetic cues to help the infant anticipate familiar activities and daily events.

An early interventionist helped Cecelia realize that Michael could better understand what was going on around him if his daily events were more predictable. In addition to the early morning and evening routines, Cecelia decided to try to increase the predictability of Michael's routines in several ways. After he finished his morning bottle, he would always get a bath. After the bath, Cecelia would put lotion on him and give him a shoulder and back massage. At bedtime, she would give him his bottle and then Kate would rock him while watching TV. Cecelia also realized that she and Michael had developed "subroutines." For example, after removing Michael's diaper and cleaning him, she would blow on his tummy and say "Okay, all dry. All dry." Then she would sprinkle powder and put a new diaper on



him, say "All done," and give him a kiss while picking him up.

Other predictable routines and subroutines followed. Before going into Michael's room, Cecelia would always announce loudly, "Here comes Mommy." She would touch his shoulders before picking him up. Before putting him in the bath, she would put his foot in the water a couple of times, which helped him to stop screaming when he was placed in the tub. Before Cecelia gave Michael his back massage, she would rub some lotion on her fingers and let him smell it.

## Module IV: Establishing Turntaking

**Goal:** To develop and increase the child's participation in familiar turntaking routines.

**Caregiver Objectives:**

- ◆ Using information gained in previous modules, learn how to encourage children to request "more" of a desired food or activity.
- ◆ Identify and extend any current turntaking routines and create new turntaking games through initiation.
- ◆ Generalize turntaking games across persons and settings.

In the first three modules, Cecelia focused on observing Michael and creating a more predictable environment. In Module IV, the emphasis was on helping him learn new behaviors. Getting him to request more of something he liked was the first objective. This was easy to do with the cinnamon and sugar icing from the cinnamon roll. Kate would let him smell it, then give him a taste with her finger. Kate learned that if she simply waited after giving Michael a taste, he would eventually open his mouth and bring his head to midline. Kate would then say, "Oh, you want another taste, don't you?"

Cecelia also used this strategy for Michael's backrubs. After massaging him for 30 seconds, she would stop and wait. Usually within 15 seconds, Michael would lift his head and extend his arms slightly, indicating he wanted more. From here, it was easy for Cecelia to develop a "turntaking game" with Michael. She simply shortened the massage to a few seconds, waited for him to extend his arms, massaged him for a few more seconds, and waited again. Although Cecelia had been worried that this would be frustrating to Michael, he seemed to catch on that they were playing a game, and this became a situation during which he consistently began to smile.

## Module V: Encouraging Communicative Initiations

**Goal:** To increase the child's rate of communicative initiations for obtaining attention from significant others, obtaining a desired object or pleasurable event, and expressing rejection.

**Caregiver Objectives:**

- ◆ Learn to increase the child's initiations by encouraging the child to express rejection of a disliked object or activity.
- ◆ Learn to increase the child's initiations by delaying an anticipated event.
- ◆ Learn how to encourage the child to intentionally initiate and to obtain the caregiver's attention.

Now it was Michael's turn to learn to initiate communication. Kate and Cecelia decided to start with one of his most anticipated events—rocking with Kate before bedtime. After Cecelia gave him his bottle, Kate would usually take Michael, sit in the rocking chair, and turn on the TV. But now, instead of immediately starting to rock as before, she would simply sit there, not moving. At first, Michael made no response at all. He got very quiet and still as though trying to figure out what was wrong. Then he would extend his arms and legs and raise his head as he does when he is upset. As soon as he moved arms, Kate would say, "Do you want me to rock?" and she would start rocking him. In this situation, Michael was learning to initiate a request that something happen, not simply request more of something that was already going on.

The last objective in this module, intentionally gaining someone's attention proved to be difficult. The goal was to teach Michael to signal for attention even when Cecelia was not close by. Since Michael was starting to vocalize more, she tried to get him to vocalize to get her to come to him. Whenever he was left alone in the infant seat, she would listen for him to vocalize. As soon as he did, she would enter the room and give him attention. But Michael's rate of vocalizing did not seem to increase. More often than not, when Michael thought he had been left alone, he would get agitated and cry.

Although Michael was still not really initiating communication to get someone's attention, Cecelia and Kate would continue to work on this goal. Nevertheless, Michael and Cecelia and Kate had changed in important ways since the beginning of the program. Cecelia felt that she understood Michael much better. She was more aware of his likes and dislikes,

better able to read his signals, and more consistent and patient in her interactions with him. Michael was also changing. He was much clearer in his communication. He seemed to communicate more with Kate and Cecelia. He was starting to vocalize more, spent more time in an awake alert state, and would even smile.

These modules and the case study were adapted and reprinted with permission from Klein, M.D., Chen, D., & Haney, M. (in press), *Promoting learning through active interaction: A guide to early communication for young children who have multiple disabilities*, Baltimore: Paul H. Brookes. (<http://www.brookespublishing.com>) 800-638-3775.



## Moon Code: A Valuable Supplement To Your Communications Arsenal

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**E**ducational needs vary greatly, but the development of a means of communication is one of the most important educational goals of individuals who are deaf-blind or multiply disabled. For many persons unable to use vision or hearing effectively, several methods of communication that rely on the sense of touch have been developed. For a variety of complex reasons, some individuals with multiple disabilities have difficulty acquiring basic literacy by means of braille or large print. This has led to a search by educators, engaged in an ongoing fight to enhance student literacy, for other tactile methods with which to supplement their teaching arsenals. Over the years, in many Commonwealth countries, Moon code has retained its importance as a core element of individualized programs for students unable to use large print, or for whom braille is too difficult. This short paper will introduce the reader to Moon code and present its benefits in an attempt to promote its increased use in programs for students with multiple disabilities.

### Moon: A Brief History

In Europe during the last two centuries, a variety of tactile reading systems, based on Roman letters, were developed. The most well-known of these, probably because of its historical importance as a predecessor of braille, is that invented by Valentin

Haüy in France (Watkins, 1987). Other early systems used in Britain and Australia included Alston type (invented in 1838) and Lucas stenographic type, based on a dot, a curve, and a straight line. In 1871, this became the standard system used at the Sydney School for the Blind (Kelley & Gale, 1998). Another similar system that endured for some years was Boston Line Type, an angular modification of Roman letters in both upper and lower case, produced at the famous Perkins School in Massachusetts in 1835. The only modern survivor of these tactile systems is the Moon code.

The Moon code inventor, William Moon, was born in 1818 at Brighton, England. He became blind in one eye at 4 years of age from scarlet fever (Middleton, 1988) and totally blind at 21. Braille had been invented in 1829, but Moon felt that it was too complicated to teach. Simplicity, as Middleton has pointed out, was his keyword. His system, initiated in 1847, is generally thought to be much easier to learn than braille, especially by older or infirm persons, because it does not require a particularly sensitive touch.

Moon, initially working from home, devised tinned sheet iron plates on which he fixed Moon code characters created from tinned copper wire and began to print embossed books (Middleton). By December 1858, after 10 years of arduous labor he had completed the whole of the Bible, 5000 pages in 60 volumes. Because he did not become blind until later in life, Moon remembered colors and shapes, but he was aware that this was not the case for people who were born blind. For example, a blind girl of his acquaintance thought that horses, like people, walked upright on two legs. So he turned his attention to the production of tactile pictures such as maps and charts of the solar system, portraits of Queen Victoria, and Euclidian diagrams.

By 1892, with the help of colleagues, 551 works in English, and 221 works in foreign languages including Hindi, Dutch, and Swedish had been produced (Middleton). The system was introduced in Australia in 1874. In 1870, a wealthy patron, Sir Charles Lowther (himself blind), presented 2000 volumes of Moon type to New York for distribution in major American cities. In 1871, William Moon received an Honorary Doctor of Laws degree from the University of Philadelphia in recognition of his work. After a visit by Moon and his daughter Adelaide to the United States in 1882, books in Moon code were being mailed from Philadelphia to all parts of the nation. Moon died in 1894. The subsequent loss of impetus in promoting Moon code has been attributed to worldwide recognition of the relative compactness and flexibility of braille (Tobin & Hill,



1989). Moon code is still being produced in England, however, for use with children and adults who have special learning needs.

## Moon Code

Moon's code consists of stripped-down and simplified versions of Roman capital letters (Mason & McCall, 1997). The letter A for example, appears without its crossbar, the letter D without its front vertical line. Nine letters of the alphabet are virtually unaltered from the standard Roman alphabet, seven letters have been slightly modified, and there are 10 new shapes (other letters and punctuation).

National Institute for the Blind (RNIB) and its National Library for the Blind. A revival of interest in the code is perhaps due to the introduction of a mechanical "Moonwriter" (Tobin & Hill, 1989). Other reasons for this resurgence have been provided by Gill (1985) and Maley (1987). In this regard, Tobin & Hill have claimed that not only is Moon a much tactually simpler system than braille for older people who become blind, it may also be "a feasible alternative for some less-able and multiply handicapped younger learners because of its smaller number of contractions." This has in fact been the case at the Royal Institute for Deaf and Blind Children at North Rocks near Sydney, where Moon script has proved a valuable supplement to the individualized pro-

a	b	c	d	e	f	g	h	i	j	k
a	but	can	do	every	from	go	have	I	just	know
Λ	U	C	D	□	∩	∩	●	I	J	<
l	m	n	o	p	q	r	s	t	u	v
like	more	not	O	people	quite	rather	some	that	under	very
⊔	⊔	N	O	⌒	⌒	⌒	⌒	—	U	V
				w	x	y	z			
				was	it	you				
				∩	>	⌒	Z			

**Figure 1: Grade 1 Moon - Produced with permission of Royal Institute for Deaf and Blind Children.**

**Note:** Moon is heavily contracted. The letter "c" also means "can", "d" means "do", and so on.

Fingers read the embossed letters by moving from left to right across the page, down to the next line, and then back across the page from right to left. In this way the reader does not lose his or her way as frequently. Middleton has asserted that Moon was fascinated to discover, many years after his invention, that his alphabet went back in style to the times of the Hittites and Ancient Egyptians and that the forwards-backwards style he had invented was called "boustrophedon" or "ox-ploughing" by the Greeks, because there was an analogy to going up one furrow and back the next. Moon's comment on his discovery was that "there is nothing new under the sun."

## Moon Code Today

Although, as Mason and McCall (1997) have pointed out, moon script readership is small today, its production is still supported by Britain's Royal

grams for multiply disabled children at its Alice Betteridge School.

There is a down side. Moon script is bulky, cumbersome, and difficult to produce. Further, it is used in a limited range of available children's literature. There are currently no written rules or international conventions on its use. Despite these drawbacks, Moon characters present a larger tactile stimuli than standard braille cells and are therefore easier to feel. Using it does not require a well-developed sense of touch. Moon code may be used as a steppingstone to learning braille and has the added advantage that sighted teachers and volunteers, as well as relatives, can help teach the code because of its obvious similarities to the familiar printed alphabet. It is, therefore, a medium immediately accessible to local community members.

## More Information:

The Moon Committee Working Group of Britain's Royal National Institute for the Blind (PO Box 173, Peterborough, England PE2 6WS) produced in 1994, an excellent kit entitled *Moon Journey: Phase 2*, a guide in large print.

RNIB (<http://www.rnib.org.uk>) also produces a comprehensive catalog of materials and supports entitled *Moon: What is available to help with reading, writing and learning*. Further, this large national agency produces a Moon Alphabet card, available free of charge, as well as a variety of teaching packages, the Moon Cat reading scheme, and newsletters.

Moon Font can be downloaded from RNIB Internet site <http://www.rnib.org.uk/wesupply/archive/welcome.htm>. Click on the moon font link to save a copy onto your own disk. RNIB also offers Moon Garden software.

Optek Systems (PO Box 277, Rydalmere, NSW, Australia 1701) markets an excellent high-tech moon embosser.

## References

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## NTAC Updates

### National Activity

#### Distance Learning Workshop (Paddi Davies)

NTAC and the state/multi-state deaf-blind projects deliver technical assistance and training to assist in meeting the needs of families and service providers of children and youth who are deaf-blind. This is not always an easy task. Two factors, geography and time, often make providing assistance difficult. New strategies for meeting needs are being explored. In February, NTAC hosted a two-day workshop on the use of distance learning methods to deliver technical assistance and training. Under the excellent instruction of Dr. Cyndi Rowland of Utah State University's Center for Persons with Disabilities, the workshop participants used the "Goodness of Fit" model to ensure there is an appropriate match between technical assistance and training outcomes, effective instructional strategies, and technology solutions.

Participants spent half a day in a computer lab learning about technologies such as web-based courses, video conferencing, chat rooms and discussion forums, and interactive CD-ROMs. Attendees from each state developed a plan to guide further exploration into the use of technology to meet their technical assistance and training outcomes. We look forward to watching the states make progress in this exciting new arena. We anticipate many positive results for service providers, families, and children and youth who are deaf-blind.

### State Activities

#### Kansas (Jon Harding)

NTAC helped sponsor a "Transition Connections" workshop last February in Kansas City. Four teams, consisting of parents and professionals, met to refine their skills in person-centered futures planning (PCFP). Each team assists one individual with disabilities ("focus person") transition from student to adult life. The PCFP process is designed to assist each team to meet the needs of the individual by providing a framework that encourages achievement of long-range goals. Two parents from Topeka inspired the group with a story of their struggle (and



ultimate success) in acquiring independent living for their children who have severe disabilities. Each team left the workshop with a plan to assist them in helping their focus person reach his or her potential.

### North Dakota (Jon Harding)

In April, the North Dakota Deaf-Blind Services Project is hosting, in conjunction with NTAC, a training opportunity for outreach workers from the School for the Blind and the School for the Deaf. The outreach workers provide assistance to students in their home environments. Attendees will learn about the unique needs of deaf-blind individuals and ways to address those needs. Tentatively scheduled topics include communication, assistive technology, effective practices, assessment, orientation and mobility, and an overview of deaf-blindness.

### South Carolina (John Eisenberg)

The South Carolina Deaf-Blind project is entering an exciting new phase. The project has recently embraced an initiative to develop transition teams throughout the state. They are looking forward to providing training sessions for new team members about how to work as a team. NTAC is looking forward to being an active member in helping the transition teams reach their goals. NTAC has also worked closely with the deaf-blind project to help develop a strong technical assistance process to increase their presence throughout the state.

### Mississippi (John Eisenberg)

The Mississippi Deaf-Blind Project is off to a fast start this year. The project and NTAC will focus its training efforts and materials development on strategies for communication and mobility for individuals who are deaf-blind. They are currently attempting to work with other agencies in the state that provide training opportunities. The purpose is to have information about deaf-blindness included in the course content of currently existing training programs on severe or profound disabilities. NTAC will be working with the deaf-blind project to help accomplish this goal. The project will also continue its current focus on transition planning and instructional strategies.

### Rhode Island (Susanne Morgan)

Interested educators and related service providers from the Rhode Island School for the Deaf (RISD) developed a team devoted to issues associated with Usher syndrome. In order to meet the needs of students with this condition at their school, they sought training and support from NTAC. The team visited Helen Keller National Center in September 1999 for two days of training that was tailored to their needs.

In March 2000, Susanne Morgan, NTAC Technical Assistance Specialist, provided follow-up training at RISD, met students and educators, and conducted an environmental assessment of the campus. A meeting to determine next steps was held.

### Missouri (Jamie McNamara)

This past Winter, Missouri completed a second training session called "Best Practices in Employment for Individuals who are Deaf-Blind." It was attended by three employment teams who work with transition age deaf-blind students to help them obtain supported employment. NTAC helped plan and sponsor the training along with the Missouri Deaf-Blind Project.

### Michigan (Jamie McNamara)

Michigan is working on strengthening an organization of parents who have deaf-blind children. A meeting to identify problems, barriers, and strategies occurred this spring. A membership retreat will be scheduled to involve more parents and identify further training needs. NTAC is supporting a consultant to work with the parent organization.



## For Your Library

### Books & Articles

#### Literacy For Persons Who Are Deaf-Blind

Miles, B., *DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind*, January 2000.

Discusses the importance of literacy for persons who are deaf-blind, the social function of literacy, and the conditions necessary for the development of literacy. The complete document is available on the web: <http://www.tr.wou.edu/dblink/literacy.htm> or order from: DB-LINK, Teaching Research, 345 N. Monmouth Ave., Monmouth, OR 97361. Tel. 800.438.9376, TTY 800.854.7013, Fax 503.838.8150. Email: [dblink@tr.wou.edu](mailto:dblink@tr.wou.edu)

### **Dimensions of Communication: An Instrument to Assess the Communication Skills and Behaviors of Individuals with Disabilities**

Mar, H. H. & Sall, N., 1999, 82 pages.

An assessment instrument designed to help teachers, educational specialists, speech-language therapists, psychologists, and other service providers evaluate the communication skills of persons with multiple disabilities, including severe or profound mental retardation and deaf-blindness. Designed primarily for persons whose communication behaviors are basic, nonconventional, and/or nonsymbolic, but can also be used with individuals who have more sophisticated language skills. A videotape is also available. The cost is \$15.00 each for the manual or videotape. Available from: Harvey H. Mar, Ph.D., St. Joseph's Children's Hospital, 703 Main Street, Xavier 6, Paterson, NJ 07503. Email: hhm1@columbia.edu

### **Transition Planning : A Team Effort**

deFur, S. H., *Transition Summary TS10, National Information Center for Children and Youth with Disabilities*, January 1999, 24 pages.

Provides information about how students, families, schools, and service providers can work together to assist students with disabilities make a smooth transition from high school to adult life. Gives an overview of transition legal requirements and describes transition teams and collaboration. The complete document is available on the web (<http://www.nichcy.org/pubs/transum/ts10.htm>) or order from: NICHCY, P.O. Box 1492, Washington, DC 20013-1492, Tel./TTY 800.695.0285, Fax 202.884.8441. Email: nichcy@aed.org

### **Questions and Answers About IDEA**

News Digest #21, 2nd ed., *National Information Center for Children and Youth with Disabilities*, January 2000, 11 pages.

Answers frequently asked questions about the mandates and requirements of the Individuals with Disabilities Education Act Amendments of 1997. The complete document is available on the web (<http://www.nichcy.org/pubs/newsdig/nd21.htm>) or order from: NICHCY, P.O. Box 1492, Washington, DC 20013-1492, Tel./TTY 800.695.0285, Fax 202.884.8441. Email: nichcy@aed.org

### **Practical Step by Step Guide for Students with Deafblindness who are Working Towards Greater Independence in the Workplace**

Schram, E. A., *Dawson Creek, B.C.: Swan Ventures*, 1998, 124 pages.

A curriculum designed by a teacher of deaf-blind students about transitioning from school-to-work. Addresses vocational choices, locating employers, preparing for interviews, communication issues, and accommodating needs on the job. The cost is \$30.00 (Canadian), shipping and handling included. Order from: Swan Ventures, 1140 102nd Ave., Dawson Creek, BC, Canada V1G 2C1. Tel. 250.782.5109. Email: ealdertn@pris.bc.ca

### **A Teacher's Guide to Communicating with Students with Deaf-Blindness**

Engleman, M. D., et al, *Teaching Exceptional Children*, 31(5): 64-70, 1999.

This article uses two case study examples of students who are deaf-blind to illustrate the basic information that teachers need in order to develop meaningful educational and communication training.

### **IDEA 1997: Implications of the Transition Requirements**

*Policy Update, National Transition Network, University of Minnesota*, January 2000, 6 pages.

A policy update about the regulatory language of IDEA 1997 transition requirements. Includes definitions of required services, exceptions to FAPE, requirements for students with disabilities in adult prisons, agency, parental and student notifications and participation, transfer of parental rights, content of the IEP, and agency responsibilities. Available from: National Transition Network, Institute on Community Integration, University of Minnesota, 103 U-Tech Center, 1313 SE Fifth St., Minneapolis, MN 55414. Tel. 612.627.4008. Email: ici@mail.ici.coled.umn.edu

### **Captured by the Net: An Internet Guide for Blind Users**

Espinola, O., *Boston: National Braille Press*: 1999, 97 pages.

A comprehensive guide about the Internet for blind users. Topics include a description of the Internet, how to choose an Internet service provider, purchasing a computer system, and setting up a computer to make it Internet ready. Available in print, braille, tape and disc from: National Braille Press, 88 St. Stephen Street, Boston, MA 02115. Tel. 800.548.7323. Web: <http://www.nbp.org>



## Videos

### **Assume Nothing: Deafblindness – An Introduction**

*West Australian Deafblind Association, 1999, 22 minutes.*

This video promotes deaf-blind awareness and may be used in conjunction with deaf-blindness training programs. Highlights 6 deaf-blind individuals, including an infant, two school-age children, and three adults. The focus is on individuality and communication. Addresses both congenital and adventitious deaf-blindness. Cost, including postage, is \$30.00 (Australian) for PAL format (the format used in Australia) or \$40.00 (Australian) for NTSC format (the format used in the US). Please make checks or bank drafts in Australian dollars. Order from: West Australian Deafblind Association, PO Box 14, Maylands, Western Australia 6051, Australia. Tel. +61 8 9272 1122, TTY +61 8 9370 3524, Fax +61 8 9370 3129. Email: wadba@nw.com.au

A second training video, *Beginning Communication with Congenitally Deafblind Children*, will be available soon.

### **Deafblindness and the Intervener**

*Utah State University: HOPE, Inc., 1998, 15 minutes.*

Discusses the effective use of interveners. Intervenors are shown working with children and youth who are deaf-blind in home, school, and community settings. Interviews are presented that give perspectives on intervention from parents, teachers, educational administrators, and interveners. Available from HOPE, Inc., 1856 North 1200 East, North Logan, UT 84341. Tel./Fax 435.752.9533.

Email: hope@hopepubl.com

Web: <http://www.hopepubl.com>

## Web Site

### **Paraeducator Support of Students with Disabilities in General Education Classrooms**

<http://www.uvm.edu/~uapvt/parasupport>

A project to develop, implement, and evaluate a model for the effective use of paraeducators to support students with disabilities in general education classes. Based at the Center on Disability and Community Inclusion at the University of Vermont.

For additional information on any of these publications, contact DB-LINK - The National Information Clearinghouse on Children Who Are Deaf-Blind

Voice: 800.438.9376

TTY: 800.854.7013

[dblink@tr.wou.edu](mailto:dblink@tr.wou.edu)



## Announcements

### **5<sup>th</sup> DbI European Conference on Deafblindness**

Deafblind International (DbI) will be holding the 5<sup>th</sup> DbI European Conference on Deafblindness, July 24-29, 2001 in The Netherlands. The theme is "Self-Determination – a life long process." If you would like to be placed on a mailing list to receive information about the conference as it becomes available, send your name, address, and format desired (normal print, Braille, large print, cassette, or diskette) to:

Stichting 5<sup>th</sup> DbI European Conference on Deafblindness

Attn. Anneke Balder

P.O. Box 222

3500 AE UTRECHT

The Netherlands

Tel. +31 30 276 99 70

Fax +31 30 271 28 92

[sdg@wxs.nl](mailto:sdg@wxs.nl)

Or go to the DbI website:

<http://www.deafblindinternational.org>

### **Camp Abilities: A Developmental Sports Camp for Children Who Are Blind and Deafblind**

Camp Abilities is a week long residential camp held at State University of New York at Brockport. The Summer 2000 session is from June 25-July 1. The camp serves blind and deaf-blind children age 8 to 18. Activities include: track and field, swimming, goal ball, beep baseball, tandem cycling, gymnastics, canoeing, judo, archery, bowling, dancing, camping and horsebackriding. The camp is totally accessible for children who are deaf-blind. All deaf-blind children have 1:1 interveners. For more information contact:

Lauren Lieberman

SUNY Brockport

Department of Physical Education

Brockport, NY 14420

Tel. 716.395.5361, Fax 716.395.2771

[llieberm@brockport.edu](mailto:llieberm@brockport.edu)

### **Self-Determination: Creating a Path to the Future**

NTAC and the Institute for Community Integration, University of Minnesota, are sponsoring a seminar for teens and young adults (ages 16-21) who are deaf-blind. It will be held during the American Association of the Deaf-Blind 2000 Conference in Columbus, Ohio, July 29-August 4. The purpose is to provide an opportunity for teens and young adults to increase their knowledge and skills in areas that

support greater self-determination. Space is limited and there are a number of eligibility requirements. For more information contact:

NTAC/HKNC  
Attn: AADB Program  
111 Middle Neck Road  
Sands Point, NY 11050  
Tel. 516.944.8900 ext. 307

## Conferences

**Early Connections: Developing Partnerships in Services to Young Children with Visual Impairments (birth to age 8)**  
June 4-8, 2000  
Vancouver, BC, Canada

**Contact:**  
Hilton/Perkins Program  
175 N. Beacon St.  
Watertown, MA 02472  
Tel. 617.972.7447  
Fax 617.923.8076  
hiltonperkins@perkins.pvt.k12.ma.us  
<http://www.perkins.pvt.k12.ma.us/whatsnew.htm>

**National Federation of the Blind Annual Convention**  
July 2-8, 2000  
Atlanta, Georgia

**Contact:**  
National Federation of the Blind  
1800 Johnson Street  
Baltimore, MD 21230  
Tel. 410.659.9314  
epc@roudley.com  
<http://www.nfb.org/conbul00.htm>

**Colorado 2000 Summer Institute on Deafblindness**  
**Remarkable Conversations: Nurturing Communication in the Culture of the Classroom**  
July 11-13, 2000  
Breckenridge, Colorado

**Contact:**  
Tanni Anthony  
Colorado Department of Education  
201 East Colfax Ave.  
Denver, CO 80203  
Tel. 303.866.6681  
anthony\_t@cde.state.co.us

**2000 AER International Conference**  
**AERODYNAMICS: Soaring to New Heights**  
July 15-19, 2000  
Denver, Colorado

**Contact:**  
Association for Education & Rehabilitation of the Blind & Visually Impaired (AER)  
4600 Duke Street, Suite 430  
P.O. Box 22397  
Alexandria, VA 22304  
Tel. 703.823.9690  
Fax 703.823.9695  
aer@aerbvi.org  
<http://www.aerbvi.org/activities/international.htm>

**American Association for the Deaf-Blind Conference**  
**21st Century - the Deaf-Blind Moves On!**  
July 29-August 4, 2000  
Columbus, Ohio

**Contact:**  
AADB National Office  
814 Thayer Ave., Suite 302  
Silver Spring, MD 20910-4500  
TTY 301.588.6545  
Tel. 800.735.2258 (MD Relay Service)  
Fax 301.588.8705  
aadb@erols.com

**18th Annual Closing The Gap Conference**  
October 17-21, 2000  
Bloomington, Minnesota

**Contact:**  
Closing The Gap, Inc.  
P.O. Box 68  
Henderson, MN 56044  
Tel. 507.248.3294  
Fax 507.248.3810  
info@closingthegap.com  
<http://www.closingthegap.com/conf>

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1-(800) AIDS-TTY

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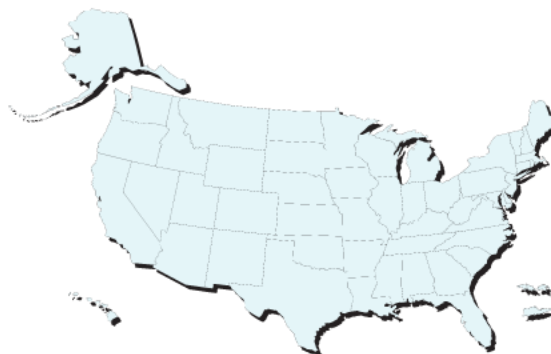
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look for TTY Service

Can E-Mail us questions at

[HIVNET@ashastd.org](mailto:HIVNET@ashastd.org)

Be sure to remember - Ask for the TTY Service to  
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### Deaf-Blind Perspectives is looking for a few good writers!

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*Deaf-Blind Perspectives* is a free publication, published three times a year by the Teaching Research Division of Western Oregon University. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education. DB-LINK and NTAC contribute staff and resources for content, editing, and publication.

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