



Cortical Visual Impairment: Guidelines and Educational Considerations

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Cortical visual impairment (CVI) has been identified as the leading cause of visual impairment in children in the Western world (Jan, Good, & Hoyt, 2004). As increasing numbers of children are diagnosed with this condition, including many who are deafblind, the importance of understanding CVI and its implications and the development of effective educational approaches have become paramount. The purpose of this article is to (a) share emerging definitions and descriptions of CVI, (b) present educational considerations and specific guidelines being followed by the multistate CVI Mentorship Project, and (c) propose questions for research on educational approaches for children with CVI.

Definition and Characteristics

Cortical visual impairment has been defined for educational purposes as “a neurological disorder, which results in unique visual responses to people, educational materials, and to the environment” (American Printing House for the Blind, 2004). Students are considered to have CVI if they have specific visual or behavioral characteristics (see Table 1). Canadian pediatric neurologist Dr. James Jan and his colleagues at British Columbia’s Children’s Hospital have contributed significantly to the identification of these characteristics (Jan & Groenveld, 1993). With new advances in medical technology, more children with neurological damage are surviving, and many have multiple and complex disabilities (Good, Jan, Burden, Skoczinski, & Candy, 2001). Dr. Jan and others have brought much needed attention to the visual functioning of children with severe damage to specific areas of the central nervous system and have provided distinctions between the acuity loss seen in ocular impairment and the type of loss seen in CVI. CVI and ocular impairment can co-exist (Huo, Burden, Hoyt, & Good, 1999), but strategies for identifying, assessing, and serving children with ocular impairment alone do not address the needs of children with CVI.

Before 1980, CVI was called “cortical blindness” and was believed to be a complete lack of visual processing by a damaged brain (Roman, in press). Little was understood about what a person with cortical blindness could see, and interventions to address the loss of visual function did not exist. Recent research about the way the brain functions and its ability to adapt have resulted in new ways of understanding the visual behavior of children with CVI (Huo et al., 1999; Giudice et al., 2002). Vision is processed throughout the brain, and discoveries about neurological pathways and connections show that improvement in visual function is possible (Roman, in press). An understanding of these findings is essential for the development of sound educational programs for children with CVI.

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Characteristics of CVI

- ◆ Normal or minimally abnormal eye exam
- ◆ Difficulty with visual novelty (prefers to look at old objects, not new, and lacks visual curiosity)
- ◆ Visually attends in near space only
- ◆ Difficulties with visual complexity/crowding
- ◆ Non-purposeful gaze/light gazing behaviors
- ◆ Distinct color preference
- ◆ Visual field deficits
- ◆ Visual latency (visual responses are slow, often delayed)
- ◆ Attraction to movement, especially rapid movements
- ◆ Absent or atypical visual reflexive responses (fails to blink at threatening motions)
- ◆ Atypical visual motor behaviors
- ◆ Inefficient, highly variable visual sense

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Table 1 Characteristics of CVI

CVI Mentorship Project

Early identification of CVI and systematic educational strategies that target its unique characteristics can enhance visual function and promote educational progress and quality of life (Good et al., 2001). Improved vision naturally increases opportunities for incidental learning, resulting in greater personal control and independence for a child. If CVI is undiagnosed, misdiagnosed, or di-

agnosed late, critical periods of learning may be missed. This points to the need for the provision of services in a timely way. As a group of interdisciplinary professionals who provide services to students with vision impairment and multiple disabilities, including deafblindness, we have identified the need for in-depth training related to screening, assessment, program planning, and intervention for learners with CVI. We represent state deaf-blind projects in Delaware, Maryland, Vermont, and West Virginia, and we have committed to a five-year collaborative multistate training initiative known as the CVI Mentorship Project. The purpose of the project is to pool resources and consolidate efforts to provide training and mentorship experiences to a small team of interdisciplinary professionals in each state. By Year 5 of the project, teams will be prepared to train, mentor, and advocate for service development related to CVI as needed within each state.

Our collaboration necessitated the examination and articulation of our beliefs about working with children who have CVI and about how to mentor educators with respect to CVI. Based on this, we have developed guidelines for working with learners, working with families, and providing quality education. They serve as a framework for the CVI Mentorship Project.

Guidelines for Working with Learners

- ◆ All children can learn.
- ◆ Children have a right to services that help them learn.
- ◆ Children make educational progress when given appropriate instruction.

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- ◆ Appropriate instruction may improve visual functioning.
- ◆ Improvement in vision positively impacts a child's performance in areas such as literacy, academics, mobility, and daily living.

Our collective experience has been that many children with CVI who have multiple disabilities, intellectual challenges, or a perceived lack of capacity for learning and literacy are less likely to have access to good systematic instruction and services that meet their unique visual functioning needs. These guidelines keep us focused on children's learning and progress and the careful planning that is needed for appropriate vision support services.

Guidelines for Working with Families

- ◆ Families are valued as full members of the educational team.
- ◆ A family-centered approach is essential.
- ◆ Parents know their children best and provide valuable information.
- ◆ Parents are reliable and accurate reporters of their children's vision-related behaviors (Roman, 1996).
- ◆ Professionals have knowledge about and are respectful of families' cultural and ethnic characteristics.
- ◆ Realistic hope and shared optimism are important.

Families play a central role in our approach to children with CVI. Their experiences, observations, and perspectives are valued and necessary and provide the foundation for positive forward-thinking teamwork.

Guidelines for Quality Education for Children with CVI

- ◆ Careful and reliable assessment is the foundation for educational decision-making.
- ◆ Systematic instruction and evaluation are essential.
- ◆ Assessment and instruction are conducted by personnel who are trained and qualified to work with children who have CVI.
- ◆ Team collaboration, problem solving, and interdisciplinary expertise are necessary for quality instruction.
- ◆ Evidence-based research drives practice.

- ◆ Education is delivered in natural settings as much as possible.
- ◆ Environmental adaptations and accommodations that match students' needs are used consistently.
- ◆ Delivery of related services is integrated across all environments and activities.

These guidelines represent good teaching and quality education for all children, including children with CVI. In our work, we find that the assessment process, instructional methods, and evaluation must take into account the unique characteristics of CVI for each child.

Carefully designed instruction and environmental adaptations help a child progress toward resolution of CVI in three phases. During Phase I, the focus is on building visual behaviors. Phase II involves integrating vision into daily routines and activities. During Phase III, a child begins to develop more typical visual functioning. (Roman, in press) During each phase the emphasis is not on vision stimulation activities but rather on carefully selected modifications and adaptations of environmental characteristics that support the student's best visual functioning at the time. This "environmental engineering" can enable a child to use his or her vision more effectively and influence a child's capacity to make progress and benefit from structured and incidental learning opportunities.

Careful consideration of a child's medical history and neurological diagnosis is critically important. The field of medicine has provided the constructs and clinical data to define CVI as a condition. It is now the responsibility of educators to bring this valuable medical information into the educational planning arena to create meaningful experiences and positive educational outcomes for children.

Research Questions

Shared guidelines have served to focus our work, but we have discovered there is still much to be learned about cortical visual impairment. We propose the following research questions for consideration:

1. What are the features of educational interventions that result in improved visual functioning for children with CVI?
2. Can the levels and phases of CVI as described by Roman (in press) be validated? What are reliable assessment methods to identify CVI characteristics?

3. What are the unique professional skills necessary for educators serving learners with CVI?
4. Is an interdisciplinary approach to serving children with CVI most effective?
5. What are the best training models for building a skilled provider workforce to serve children with CVI?

Our hope is that these questions will promote a national dialogue that draws upon expertise and knowledge from a variety of fields to improve our knowledge about CVI and the effectiveness of services for children with CVI. Ultimately, enhanced visual functioning for children and youth with CVI will bring about a better quality of life for children and their families. For more information about CVI, visit the Web site of the American Printing House for the Blind at <http://www.aph.org/cvi>.

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Children with Usher Syndrome: Learning to Cope through Work with Mentors

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The Center for Deaf-Blind Persons of the Beth David Institute in Israel has developed an innovative program for children with Usher Syndrome. Through work with mentors, children learn about their diagnosis and receive exposure to a successful coping model. The program is open to every child with Usher Syndrome in the entire country, including Jews, Muslims, and Christians. It aims to serve 40 children a year.

Based on more than a decade of experience working with deaf-blind individuals and inspired by the book *Usher Syndrome in the School Setting* (Miner & Cioffi, 1996), we have concluded that children with Usher Syndrome need early contact with adults who also have Usher Syndrome. The children can easily identify with these adults, and interaction enables them to learn about progressive vision loss in a positive setting, unlike cases we have seen of children who become depressed by doctors who provide misleading information and make fatalistic statements such as “You’re going blind.” We have found that children are inspired by contact with young, vibrant, and successful persons with Usher Syndrome who are enjoying an active life.

This program, which is the first of its kind in Israel, took shape under the professional and personal guidance of Yael Halevi. Yael, who has Usher Syndrome herself, holds a BA in Literature and is a certified movement therapist. The program begins by identifying children between the ages of 10 and 21 and simultaneously recruiting and training young adults with Usher Syndrome to become mentors. Requirements for mentors include a certain level of maturity and life experience, good communication skills, high motivation, and an open and accepting attitude toward their deaf-blindness. The mentors participate in a mandatory training program to learn how to teach the children to function with Usher Syndrome at work and leisure and how to set an example of success despite obstacles. In addition to the initial training, the mentors all receive weekly guidance and learn how to approach sensitive issues that the children may raise, such as the desire for a

driver's license or when and how to tell friends that they have Usher Syndrome.

Over the course of a year, the mentors meet with the children weekly—individually or in small groups. Through this structured contact, the children learn very gradually about Usher Syndrome through the presentation of facts and personal examples. They gain skills and knowledge to help them broaden their horizons and be willing to accept help from others. They also learn to come to terms emotionally with their physical limitations. This contact is critical to future success in that it helps children gain a foundation of independence, self-esteem, and confidence. As they progress, they tend to become more open to learning mobility skills and alternative communication methods.

A double-empowerment process takes place during this program. The children learn useful skills and coping strategies, and the mentors gain valuable work experience that may lead to new career opportunities. The mentor training they participate in also provides them with a valuable support group. Most have never before participated in a similar group situation.

Early mentoring offers action and the hope of success as opposed to passivity and a feeling of impending failure. This program benefits not only the deaf-blind community, but also Israeli society as a whole. Instead of supporting these children when they become adults, it gains members of society who make valuable contributions.

The Center for Deaf-Blind Persons provides comprehensive rehabilitation, educational, and social services for the deaf-blind population in Israel. We continually develop and run a wide range of innovative programs and strive to enable deaf-blind individuals to live full and independent lives, to as great a degree as possible. The Center encourages all people with deaf-blindness to learn about their disability and helps them to cope and play an active role in their own rehabilitation and that of others.

For more information about this or other programs, please contact Elias Kabakov, professional director, Center for Deaf-Blind Persons, by mail at P.O.B. 9259 Tel Aviv, 61092 ISRAEL, by fax at +972-3-6316419, or by e-mail at elias@cdb.org.il.

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New Master's Degree Program in Severe Disabilities with an Emphasis on Dual Sensory Impairment in Mississippi

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In spring 2004, there was a new opportunity for teachers and service providers in Mississippi who work with children and adults who are deaf-blind. The University of Southern Mississippi (USM), in collaboration with Texas Tech University (TTU), has developed a master's degree program in severe disabilities with an emphasis on dual sensory impairment. The program accepts individuals who have an undergraduate degree in education or a related field and at least two years experience working with individuals with multiple disabilities. Graduating students are obligated to provide two years of service in Mississippi after completing the coursework. The program aims to train up to 60 people over a 5-year period to fulfill a long-felt and completely unmet need in the state of Mississippi. Funding for the program is provided through a grant awarded by the U.S. Department of Education. It covers students' tuition, books, travel, and child-care expenses.

The program's focus is helping students to learn and implement the *Competencies for Teachers of Learners Who Are Deafblind* set forth by the Perkins National Deafblind Training Project (McLetchie & Riggio). Most of the courses are provided on-line. Other formats include CD-ROMs, videotapes, teleconferencing, videoconferencing, and e-mail. Students are required to be on the USM campus for one day each semester for scheduled face-to-face meetings with instructors. The program includes six courses provided by TTU and three courses provided by USM. The TTU courses are:

- ◆ Programs and Services for Students with Dual Sensory Impairments
- ◆ Physical Aspects Affecting Students with Visual Impairments and Multiple Disabilities
- ◆ Basic Orientation and Mobility Skills for Students with Visual and Multiple Disabilities
- ◆ Physical Aspects of Hearing for Students with Dual Sensory Impairments
- ◆ Methods and Materials for Teaching Students with Dual Sensory Impairments

- ◆ Communication and Child Centered Assessment for Students with Deafblindness

The USM courses are:

- ◆ Administration and Disability Law
- ◆ Applied Research
- ◆ Transitioning to Adult Services

In addition, a class on assistive technology is available through a contract with Mississippi State University.

Two observation experiences are also required—one in-state and one out-of-state. These provide opportunities for students to observe experienced teachers in different settings. The observations typically last from one to two weeks. In-state observation experiences are facilitated by the Mississippi Deaf-Blind Project, which is housed at USM. Out-of-state observation sites have included Perkins School for the Blind, Texas School for the Blind and Visually Impaired, the Helen Keller National Center, the Arkansas School for the Blind, and a public school system in Florida. Additional sites are being added. Dr. Linda McDowell, director of the Mississippi Deaf-Blind Project, has worked diligently to secure sites that provide valuable experiences for students.

In December 2005, the program successfully graduated its first group of 15 students. A second group of 13 students is scheduled to graduate in December 2006, and a third group of 11 students, who began the program in January 2006, will graduate in December 2007. The application process for a fourth group is currently underway. At this time, the program is only available to students in Mississippi. However, as interest in the program has increased, discussion has begun about the possibility of accepting out-of-state students in the future.

Feedback from the first group of students has been positive. One particular benefit that many have mentioned is how helpful it is to have a statewide network of colleagues with expertise in deaf-blindness to call on for support. Following are some additional student comments:

The information I learned that specifically focused on individuals who are deaf-blind could easily be adapted to fit individuals with other disabilities.

The program increased my advocacy skills for individuals who are deaf-blind.

The program benefited me not only in the area of deaf-blindness but in the field of special education in general. I have a much deeper under-

standing of the laws that protect all special education students.

The experience was positive and encouraging, because it forced me to see possibilities in each and every person who is deaf-blind. I also feel that I now have a support system in the state.

Six students in the first group of graduating students were directly affected by Hurricane Katrina. Some did not have power or Internet access for up to two months. Other class members were able to help them by providing support and access to class notes, assignments, and materials.

The master's degree program is a dream come true for the many people who recognized a need for more trained teachers and service providers in Mississippi and who worked hard to create and implement the program: Linda McDowell, Ph.D. (USM), director of the Mississippi Deaf-Blind Project and author of the grant that secured funding for the program; Liz Grantham (USM), administrative assistant to Dr. McDowell; Janet Salek (USM), instructor; Roseanna Davidson, Ed.D. (TTU), instructor; Effie Laman (TTU), research instructor; Esther Lucy (TTU), administrative assistant to Roseanna Davidson; and the graduating class of 2005.

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Personal Perspectives

Services for Individuals Who Are Deaf-Blind Must be Lifelong

William and Laura Hull
South Carolina

Like many parents of children who are deaf-blind and have multiple disabilities, we have for years been fighting for appropriate services for our son. This began with a struggle to get appropriate educational and related services during his school years and has continued now that he is an adult. Socialization, daily activities, stimulation, overall care, and housing fall on us, the parents, as we ourselves are aging. This problem must be addressed. Parents and professionals need to work together to develop programs and approaches that meet the needs of individuals who are deaf-blind throughout their lives.

Background

Our son's life began with stormy events. At 3 pounds 12 ounces, he struggled to survive. He had a soft cleft palate, chronic respiratory problems, four adult-size hernias, rectal prolapse, seizures, and problems nursing. He spent the first three years of his life in and out of pediatric intensive care units at various hospitals. At 3 months of age he had a gastric tube inserted into his stomach for tube feedings and was tube fed until age 7. It was determined by age 2 that he had severe hearing loss. At age 3 he was diagnosed with a rare genetic syndrome and received glasses and hearing aids. By age 7 he was found to have severe cataracts requiring surgical removal, and at age 15 he had laser retina surgery to save his sight. Unfortunately, he was declared legally blind by age 16.

During his school years, we had to battle for suitable programs, even to the extent of going through due process. The lack of appropriate services and another student's dangerous behavior forced us to remove our son from public school at age 17. We established our own home teaching program and used two hospitals for occupational and speech therapies. Our state's deaf-blind project coordinator provided counseling and support and worked with our son's speech and occupational therapists. Her services were invaluable because she believed in our son. We saw his sign language vocabulary increase significantly. After several months in our home program, it was determined that he knew 175 to 200 signs expressively and about 500 receptively. Now, at age 25, he knows approximately 275 to 300 expressively and 500 to 600 receptively. The deaf-blind project coordinator's services and encouragement inspired all of those who worked with our son to believe in him and his achievements.

Adult Services

The struggle to obtain adequate services recurred after our son turned 21. People with disabilities, especially deaf-blindness, often have limited or no local individualized programs available. Some people with disabilities do find jobs, but most are limited to sheltered workshops. Unfortunately, there are too few qualified service providers because most are not trained to deal with people who are multiply disabled, deaf-blind, and nonverbal. At one disabilities day program we viewed, we found that no one knew sign language or knew how to communicate with people with communication problems, let alone deaf-blindness. We observed participants with disabilities sitting around

watching TV, sleeping on desks, or with nothing to do, and we saw only a few working. We knew this program would not be productive or enhancing for our son so he remained with us. To assist him with socialization, we helped a group of disabled individuals to organize their own club known as People First. The members are in charge, run the meetings for the most part, and choose goals and objectives. This club is going strong after seven years.

Finding and retaining qualified service providers is extremely difficult. In 2000, our son began receiving services from a community support program that provides assistance to individuals with disabilities at home and in the community. The program provides rehabilitation support specialists to assist with daily activities like self-help skills, communication, shopping, and eating out. The experience began fairly well with a support specialist who knew sign language, but this person left to return to a full-time job at the end of the summer. The program had repeated difficulty locating and retaining support specialists who knew sign language or were able to learn to communicate with our son. Over a 5-year period we had four different support specialists, and between each there were extended periods of time (once for as long as 27 months) when our son had no one to work with him. He was recently terminated from the rehabilitation program because no one could be found to work with him. Presently, we are considering looking again at the day program we saw earlier, because new grant monies are bringing about some positive changes there. We hope this works out because our son needs space, socialization, and time away from us. After fighting for years for services, we need a break too.

A New Approach

Fortunately, there is hope with a new model approach on the horizon to help those with deaf-blindness. It is the intervener model, for which there is a national task force. Interveners are trained individuals who work with children who are deaf-blind and provide support in areas such as communication, daily care, and mobility. The trained intervener serves as a deaf-blind person's eyes and ears and facilitates communication. Interveners are a must for school-age children because a deaf-blind child's educational advancement is at stake. It is just as important to use the intervener model with many adults who are deaf-blind. We must support a national movement for the provision of trained intervener services throughout life because all children one day reach the magic age of 21. No one should be cut off from their life and the

environment around them. The intervener model is a good example of a better way to help people with deaf-blindness and multiple disabilities. To bring about positive changes, parents, guardians, and professionals must band together to support this new model approach and its task force.

Editor's note: The National Intervener Task Force is an informal network of professionals and parents interested in issues related to the training and use of interveners. The focus of the task force so far has been on interveners in educational and early intervention settings, but expanding the focus to adults who are deaf-blind is possible if there is interest and individuals willing to participate and work on these issues. For more information, contact Linda Alsop, SKI-HI Institute, Utah State University (phone: 435-797-5598; e-mail: lalsop@cc.usu.edu).



A Model for Paraprofessional Training in Deafblindness

Linda Alsop
SKI-HI Institute, Utah State University

The use of paraprofessionals with children and youth who are deafblind continues to increase. The Individuals with Disabilities Improvement Education Act of 2004 (IDEA) acknowledged and strengthened the role of the paraprofessional in the provision of special education and related services. It clearly states that paraprofessionals and assistants who are properly trained and supervised may assist in the provision of special education and related services to children with disabilities. The No Child Left Behind Act mandates the availability of qualified staff for all students. Paraprofessionals who work with children and youth who are deafblind not only need training and specialized skills, but they must also meet state standards for paraprofessionals. Currently, there are no preservice training programs in the United States designed specifically for paraprofessionals in deafblindness that also interface with state paraprofessional standards.

The Consortium for National Paraprofessional Training in Deafblindness is addressing this lack through a model for distance education. Program components include:

- ◆ Offering three semesters (nine credit hours) of on-line coursework in deafblindness that utilize the best practices in distance-education instructional strategies;
- ◆ Field testing the three courses at three community colleges in Utah, Massachusetts, and Texas, and at one 2-year program of study in Arkansas;

- ◆ Embedding the three courses as electives into existing programs of study at each site, so that students can take the three courses in deafblindness alone or as part of an associate degree program;
- ◆ Ensuring that the competencies for the coursework interface with each state's standards for paraprofessionals; and
- ◆ Coordinating with state deaf-blind projects to involve them in recruitment and practicum efforts.

The coursework is scheduled to begin in the fall of 2006 and will be offered at the following sites: Salt Lake Community College, Utah; Mount Wachusett Community College, Massachusetts; The University of Arkansas at Little Rock; and South Plains College, Texas.

The project is funded by the U.S. Department of Education's Fund for the Improvement of Postsecondary Education (FIPSE). For additional information, contact:

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A Common Language Theresa Vincent

She speaks
a common language
of touch, gesture,
a turn of the head,
the brightness
in her eyes.

In this
silent dialect,
with the reach
of a hand,
she asks,
are you there?

Research Update

CHARGE Development in Adolescence

Timothy S. Hartshorne
Central Michigan University

Interest in CHARGE Syndrome has increased dramatically since it was initially identified. Although the first reported cases were published in 1979, knowledge of the condition grew slowly. Only a few articles were published each year until 1985, when there were 6. By 2005, there were more than 30. Prior to the identification of a gene in 2004, diagnosis relied on the identification of characteristic features of the syndrome including coloboma (missing piece of the eye), choanal atresia (blocked nasal passages), cranial nerve abnormalities (particularly those involved with hearing, swallowing, balance, and the face), and the distinctive CHARGE-shaped ear (Blake et al., 1998). Heart, kidney, hand, abdominal, and spinal problems are less common features. A difficulty with this type of diagnosis is that the features vary in their presence or absence, and when present, in their severity. A heart defect, for example, may be very minor, or it may be extremely complex and life threatening.

Children diagnosed from the late 1980s to the early 1990s were elementary school age or younger and typically had severe characteristics. Fewer older children and adults were identified at that time, probably because they happened to be less severely affected. In earlier decades, individuals with serious, less treatable characteristics would not have been likely to survive. As a result, knowledge of the natural history of CHARGE had to develop along with the children identified in the 1980s and 1990s, so many of the less common features were only identified as the population aged.

The first large Deaf group of children to be diagnosed as infants is now in late adolescence or early adulthood, therefore, our knowledge of adolescent development for persons with CHARGE is extremely limited. A number of questions have been raised, but there are few answers, and appropriate treatment protocols have not been identified. We know that puberty is usually delayed, but we don't know the extent of the delay or whether there are useful and appropriate treatments. We know that many children develop osteoporosis, but we don't know how early this occurs or whether it can be prevented. We suspect that medical complications emerge during adolescence, but

we're not sure what or how common they are. Behavioral challenges are common in children with CHARGE, but we don't know if challenging behaviors increase, decrease, or otherwise change during adolescence.

To better understand these issues, five experts have joined together for a research initiative: Kim Blake, a clinical pediatrician from Dalhousie University in Nova Scotia; Meg Hefner, a genetic counselor at St. Louis University Hospital; Jeremy Kirk, an endocrinologist from Birmingham Children's Hospital in England; George Williams, a pediatrician from Sydney, Australia; and myself, a psychologist from Central Michigan University. We are currently conducting a pilot study of 32 children, ages 9 to 21, from the U.S., Canada, England, New Zealand, and Australia. It is a complicated study because in addition to more psychological measures, such as adaptive behavior, executive function (cognitive skills that control and regulate thought and action), and activity levels, it involves medical testing and reports. For example, we are requesting blood work to look at pituitary functioning and measures of bone age and density. The information obtained is likely to be of vital importance in the medical, educational, and psychological management of adolescents with CHARGE. After completion of this study, we hope to conduct a multiyear investigation.

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Request for Feedback on Assessment Instruments

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Oregon Health & Science University is in the third year of a grant from the U.S. Department of Education to study and validate methods to assess the communication and cognitive skills of 2- to 8-year-old children who are deafblind. We are seeking feedback on assessment instruments from professionals and parents.

We would like feedback from professionals who have administered any of the following to children age 2 to 8 who are deafblind (within the past 5 years): *Callier-Azusa* (Stillman); *Carolina Developmental Profile* (Harbin & Bourland); *Hawaii*

Early Learning Profile (HELP) (Parks); *INSITE* (Morgan & Watkins); *Oregon Project* (Anderson, Boigon, & Davis); and *Vineland* (Sparrow, Balla, & Cicchetti).

We would like feedback from parents who have access to the results of any of the following instruments used within the past 2 years to evaluate their 2- to 15-year-old children: *Callier-Azusa* (Stillman); *Carolina Developmental Profile* (Harbin & Bourland); *Communication Matrix* (Rowland); *Dimensions of Communication* (Mar & Sall); *Hawaii Early Learning Profile (HELP)* (Parks); *Home Talk* (Numerous authors, OSEP Project); *Infused Skills Assessment* (Hauser & Hagood); *INSITE* (Morgan & Watkins); *Oregon Project* (Anderson, Boigon, & Davis); *School Inventory of Problem Solving Skills* (Rowland & Schweigert); and *Vineland* (Sparrow, Balla, & Cicchetti).

Professionals will be asked to fill out a form to evaluate the instrument and will be offered a \$20.00 gift certificate for their efforts. Parents will be asked to provide copies of assessment results, copies of their child's latest IEP or IFSP, and will be asked to evaluate the instrument. They will be offered a check or gift certificate in the amount of \$50.00 for their efforts. For more information, contact:

Charity Rowland, Ph.D., Project Director
Oregon Health & Science University
Phone: 503-494-2263
E-mail: rowlandc@ohsu.edu

For Your Library



Tactile Learning Strategies: Interacting with Children Who Have Visual Impairments and Multiple Disabilities (Video or DVD—62 minutes)

Deborah Chen & June Downing New York: AFB Press, 2006.

Using narration, interviews, and the detailed experiences of children and their families, this video illustrates strategies to help children who are visually impaired and have multiple disabilities learn through touch. English and Spanish versions are on the same tape. Available from AFB Press. Phone: 800-232-3044. E-mail: afborder@abdintl.com. Web: <http://www.afb.org>.

2006 AccessWorld® Guide to Assistive Technology Products

AFB Press, 2006.

This guide provides detailed profiles of over 200 products and also includes a comprehensive list of objective product evaluations previously published in AccessWorld, AFB's technology magazine Available from AFB Press. Phone: 800-232-3044. E-mail: afborder@abdintl.com. Web: <http://www.afb.org>.

The Intervenor Professional Network (Web site)

<http://www.deafblindresources.org>

The Intervenor Professional Network is an international Internet resource on deafblind communication strategies. It is intended to promote communication between parents, intervenors, paraprofessionals, and anyone working with individuals who are congenitally deafblind, for the purpose of exchanging information and strategies. The site will promote communication by providing a forum, chat room, and comment driven blogs that allow visitors to communicate with each other locally and internationally. For more information, contact Niall Brown at niallbrown@deafblindresources.org.



Conferences and Events

Educating Students with Deafblindness: National Conference (featuring Jan van Dijk) July 21–26, 2006 Greensboro, North Carolina

Dr. Jan van Dijk is a world renowned educator from the Netherlands who has pioneered teaching approaches for individuals who are deaf-blind. This national conference is sponsored by the North Carolina Deaf-Blind Project, the NC Department of Public Instruction Exceptional Children Division, and Western Carolina University. The main topics will address behaviors, family dynamics, social relationships, literacy, and technology for students who are deaf-blind and will also include a panel of experts presenting information on innovative educational practices from around the world. Early Bird conference registration deadline is May 29, 2006. **REGISTER EARLY!** For more information go to <http://edoutreach.wcu.edu/continuing/deaf-blind> or contact Chris Jones, Coordinator, North Carolina State Deaf-Blind Project. Phone: 919-807-3991. E-mail: cjones@dpi.state.nc.us.

Colorado Summer Institute on Deafblindness
August 7–9, 2006
Breckenridge, Colorado

The theme is “Links to School and Life Success: Communication and Literacy for Children with Deafblindness and Other Significant Support Needs.” The featured speakers are Susan DeCaluwe and Lisa Jacobs, educational consultants for the New England Center Deafblind Project at Perkins School for the Blind. The Institute is primarily for Colorado families and service providers, but participants from other states may be welcome if space is available. For more information contact Tanni Anthony, Colorado Department of Education. Phone: 303-866-6681. TTY: 303-860-7060. E-mail: anthony_t@cde.state.co.us.

HKNC 2006 Senior Adult Program

Helen Keller National Center (HKNC) in Sands Point, New York, announces its 2006 Senior Adult Training Program. Senior adults, age 55 or older, have a unique opportunity to learn adaptive skills related to loss of vision and hearing, obtain resource information, develop coping strategies, learn about technology for independent living, and have fun with other senior adults experiencing combined vision and hearing loss. There will be two 2-week seminars:

- ◆ September 10–22, for individuals who are blind or visually impaired and hard of hearing and who do not use sign language;
- ◆ October 1–13, for individuals who are blind or visually impaired and deaf and who use sign language as their primary means of communication.

For more information, contact Paige Berry, coordinator, HKNC Senior Adult Program, at hkncpaigeoap@aol.com, or visit the HKNC Web site at <http://www.hknc.org> and click on “Senior Adult Program.”

7th Canadian Conference on Deafblindness 2006
September 21–24, 2006
Winnipeg, Manitoba

The Canadian Deafblind and Rubella Association has chosen “Celebrating Potential” as the theme for this conference. For further information contact Gitta Schwartz, Suite 201-1100 Concordia Ave., Winnipeg, Manitoba, Canada R2K 4B8. Phone: 204-949-3733. E-mail: gschwartz@imi-mb.com. Web: <http://cdbra-mb.com>.

Usher Syndrome and Related Disorders
Symposium
October 4–6, 2006
Omaha, Nebraska

This meeting will bring together scientists from different disciplines in order to facilitate collaboration and encourage communication between researchers. The format of the meeting will be a series of round tables with international experts on various aspects of Usher syndrome. See the following web site for more information: http://www.sahlgrenska.se/vgrtemplates/Page___38539.aspx, or email William Kimberling at kimber@boystown.org



Announcement

New Screening Tool for Usher Syndrome

Dr. William Kimberling at Boys Town National Research Hospital has announced a new tool to screen for Usher Syndrome. USMChip is a microchip that can test a saliva sample for all known types of Usher Syndrome (currently, there are eight) by checking for approximately 420 known DNA mutations. The success rate is expected to be between 65% and 75% and should improve over time as new mutations are identified and included on the chip. The cost of the test is \$200 per person, which makes it an ideal tool for screening. Previously, testing was only available through a process known as sequencing, which could cost thousands of dollars and required DNA obtained from a blood sample. The National Center for the Study and Treatment of Usher Syndrome welcomes new participants interested in screening for Usher Syndrome. This involves purchasing the chip and sending a saliva sample by mail. Once tested, results will be returned in 2 to 4 months. Interested persons should contact Dr. Kimberling directly.

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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.

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