

Educational and Behavioral Implications of Missing Balance Sense in CHARGE Syndrome

by David Brown, CDBS Educational Specialist

When this condition was first named in 1981, the six diagnostic criteria that were used to make up the acronym 'CHARGE' were thought to be the main features of the condition, but since then over 40 associated anomalies have been identified (CHARGE Syndrome Management Manual of the CHARGE Foundation, and see <http://www.widerworld.co.uk/charge/whatis.htm>), which makes CHARGE, medically and developmentally, one of the most complex conditions that we know. Children with CHARGE are also likely to be amongst the most truly 'multi sensory impaired' people you will ever meet, having difficulties not just with vision and hearing but also with the senses that perceive balance, touch, temperature,

pain, pressure, and smell. The many different anomalies associated with CHARGE will each impose different, varying, and often, conflicting demands upon the child. One of the most pervasive but least understood of these is the missing sense of balance.

Balance and Low Tone

Balance

It is thought that most people with CHARGE have no balance sense due to the malfunctioning or absence of the semicircular canals (the receptors of the balance sense) in the inner ears. The semicircular canals play a crucial role in organizing sensory inputs in all the other sensory channels, so this anomaly has a profound affect on all areas of functioning for the whole life of the child, **but its importance and impact is usually over-looked and underplayed**, especially **once the child is standing and walking**. In the early years the child is likely to show the following:

- very low muscle tone ("floppy muscles")
- very poor head control and a generally poor ability to resist against gravity
- strong postural insecurity when held upright or sat on a lap
- a marked preference for laying flat on the back (supine), and later on the sides too, for long periods of time for most activities
- very delayed mobility, then unique movement patterns including shuffling backwards head-first in supine, shuffling sideways in supine, 5-point crawling (using both knees, both arms and the forehead down on the floor as an extra support)

In This Issue

ETIOLOGIES

Educational and Behavioral Implications of Missing Balance Sense in CHARGE Syndrome.....	1
Leading Causes of Deaf-blindness	4
Etiologies Fact Sheet:	
English.....	5
Spanish.....	7
Is Knowing My Son's Etiology Really That Important?.....	9
A Big Thank You.....	9
Two Excellent New Resources.....	10
Educational Assessments.....	10
Mark Your Calendar!	11

(continued on page 2)

Missing Balance Sense in CHARGE Syndrome (continued from page 1)

- floor sitting with the legs in a “W” position to give a broader and more secure base
- extreme fatigue after trying to resist gravity (e.g., by sitting or holding the head erect) for short periods of time

In later childhood and adolescence the problems with fatigue, postural control, and sitting or standing unsupported will be less evident but still present. Sometimes the student will benefit from using an adapted chair, with arms and a footrest, possibly also with a tilted seat to encourage more active sitting. There may still be a great need to rest the head on one or both arms or even down on the desktop itself, in order to read or write. Some older children and teenagers can seem to function quite well at their desk for extended periods of time, but they then need periodically to get into a horizontal position to relax and to re-charge their energy levels for the next exertions. They may also need these periods in the horizontal position to reorganize their sensory system using behaviors like leg kicking, arm waving, hyperventilating, or gazing at bright light. Extended periods of standing still and entirely unsupported are usually particularly challenging. Regular input from a physical therapist is very important for all children with CHARGE, but the therapists will need to be informed about the high frequency of severe balance problems in this population and about the implications of this.

Low Muscle Tone

Very low muscle tone is partly an outcome of severe balance problems, but is also associated with low vision, breathing difficulties, and generally reduced sensory inputs hence reduced perceptual awareness, and the problem is then compounded by the lack of motivation to move and the resulting lack of “exercise”. Saving reactions, standing, cruising, and independent walking usually develop very late (one British survey found a mean age of 4 years for independent walking). When children do walk there is often a characteristic gait, some aspects of which may remain evident for many years—feet spaced widely apart, knees bent, body rolling from side to side with each step, feet sliding along the floor or being planted down very firmly on the floor (maybe several times, almost like patting the floor with the foot) with each step, arms held up like a tightrope walker. Some children walk with repeating swaying circular movements of the upper body and head, as if trying to keep some awareness of the danger areas at the parameters of safe posture. On-going monitoring by a Physical Therapist is important because there is a high risk of the development of scoliosis (curvature of the spine) in later childhood and the teenage years: this may then require therapy treatment

and environmental adaptations, the wearing of a body brace, or even spinal surgery in acute cases.

Equilibrium

Postural security and a good sense of equilibrium depend upon the effective development and functioning of three different but interdependent sensory systems (known as the ‘Equilibrium Triad’)—these are the vision sense, the balance sense, and the tactile/proprioceptive senses. In people with CHARGE all of these sensory systems are likely to be missing or impaired in some way, which explains the slow development of large motor skills and mobility, but also makes it remarkable that the majority of children with CHARGE do eventually stand up and walk. Any input that helps to improve the functioning of any of the senses in this Equilibrium Triad can, therefore, be regarded as making a contribution to the development of independent standing and walking.

Balance and Vision

There are strong links between the balance sense and vision, and problems with balance may affect the ability to maintain a stable visual field, to follow moving objects smoothly with the eyes, and to differentiate whether it is the object or oneself that is moving. Some children may appear to be totally blind if their postural security is challenged, but may show some well-developed visual (and other) skills once they are flat on their back or side on a stable surface. As they get older children may use residual vision to help them to stay upright, compensating for having no balance sense by using the strong visual impressions made by horizontal and vertical lines in a room (e.g., walls and the edges of windows, doors, table tops, and wall-mounted pictures); they may have much less equilibrium outdoors where these strong visual markers are largely absent. One result might be a reluctance to go outdoors (e.g., during recess at school), and another might be an inability to perform certain tasks outdoors (e.g., playing soccer) that are carried out very well indoors. For children who are reading, the use of a typoscope (a letter-box shaped frame) can help by isolating one single line of text at a time.

Balance and Hearing

Several writers have emphasized the links that exist between the balance sense and the ability to process sound and to develop spoken language. This has obvious implications for people with CHARGE, and a collaborative approach that brings together a teacher of the Deaf and hard of hearing, a speech therapist, and an occupational

(continued on page 3)

therapist trained in sensory integration therapy (or any combination of these) should be very helpful.

Sensory Integration Dysfunction

This problem is inherent in CHARGE, and significant difficulties caused by poorly modulated sensory systems are very common. Many behaviors, some of them apparently contradictory, could indicate the need for a sensory integration (SI) assessment by a trained occupational therapist:

- rejection of textures in the mouth apart from pureed food **but** mouthing of all kinds of non-food items (e.g., stones, wood, cloth, soil)
- inability to chew and bite on solid foods but excessive biting and chewing on non-food items/persistent teeth grinding
- rejection of certain tactile inputs as if they are painful **but** apparent non-awareness of certain other tactile inputs (which for us might be painful!)
- extreme postural insecurity when sat or stood by another person **but** pleasurable responses to strong rhythmic movement experiences (e.g., rocking, bouncing, swinging)
- periods of frantic over-activity **but** also sudden periods of apparent 'burn-out'
- abnormally high pain thresholds
- very delayed awareness of bowel and bladder movements
- disturbed and inconsistent sleep patterns
- behaviors that seek and provide very strong sensory inputs, e.g., self-biting or scratching, skin picking, spinning, rocking, bouncing, shoulder shrugging, leg swinging, hand flapping, self-slapping, as a way of getting the body reorganized

Some typical techniques suggested by a therapist following an SI assessment might include brushing protocols, rhythmic joint compression, deep tissue massage, vibrotactile input, a range of large movement activities, and the use of weighted clothing. A variety of outcomes might be anticipated from implementing these techniques, including improving the child's ability to attend to sensory information in the environment, improving muscle tone, improving awareness and tolerance of touch, improving attention span and decreasing distractibility, reducing the need for self-injurious behavior, improving sleep patterns, and generally increasing the child's ability to

remain both alert and calm in stressful situations. This kind of SI perspective might be needed, regularly or periodically, throughout the child's life and should never be automatically regarded as a one-time 'fix'. I believe that every person with CHARGE would benefit significantly from having at least intermittent SI assessment by a suitably qualified occupational therapist.

There must be all sorts of different reasons why children with CHARGE persevere, but I think it may often be a technique that they use to establish a firm physical, emotional, perceptual, and cognitive 'base' each time before they move on into comparatively uncharted territory. Successful teaching often depends on allowing for this need and spending some time alerting the child to the fact that you are there, who you are, what you are going to be doing together, how it will be done, and so on. The child may need considerable time, and help, to establish a secure and stable physical base as a first priority in every interaction.

In Conclusion

Teamwork – this is all much more complicated than we will ever truly realize, and many disciplines and viewpoints will need to be discussed and considered if appropriate programs are to be created and maintained.

Priorities – with such complexity it is always difficult to decide on the best priorities from moment to moment, day to day, and week to week. Often, established low vision, or hearing impaired, or physical therapy (or whatever) priorities may have to be put to one side so that the emphasis can go on to other things. Great creativity will be needed to ensure that the educational program is flexible and alert to the needs of the moment, but also has the balance needed to address all the many and complex needs of the child as effectively as possible.

One thing at a time – only the clearest view and the strongest empathy will help people to gain any insight into what an activity really means for the child. "What am I trying to do at this moment/in this activity?" is always a good question to have in our minds, but a more urgent question might be "What is the child's perception of what I am trying to do at this moment/in this activity?" In other words, what are likely to be the main demands upon the child's attention as a result of the way I have organized this session?

Behavior – parents and professionals often report themselves puzzled, confused, and frustrated by the

(continued on page 4)

behavior patterns of children with CHARGE, and there is no doubt that these children can be particularly challenging people with whom to work and, especially, to live. There has been a long-standing debate about "CHARGE behavior" amongst families with children with CHARGE, and recently some research into behavior has been begun in the US, in the UK, and in France. I hope that some of the information and thoughts in this paper will help people to develop their own insights into why certain things happen the way that they do. Above all, I hope this paper will remind people of the immense difficulties these children face in almost everything that they do, and, as a consequence, of the very high levels of stress with which they must live for much or even all of their lives. Time spent trying to reduce stress levels, and trying to give the children acceptable strategies for doing this for themselves, must be one of the most precious gifts we can offer them, and one of the biggest favors we can do ourselves as educators.

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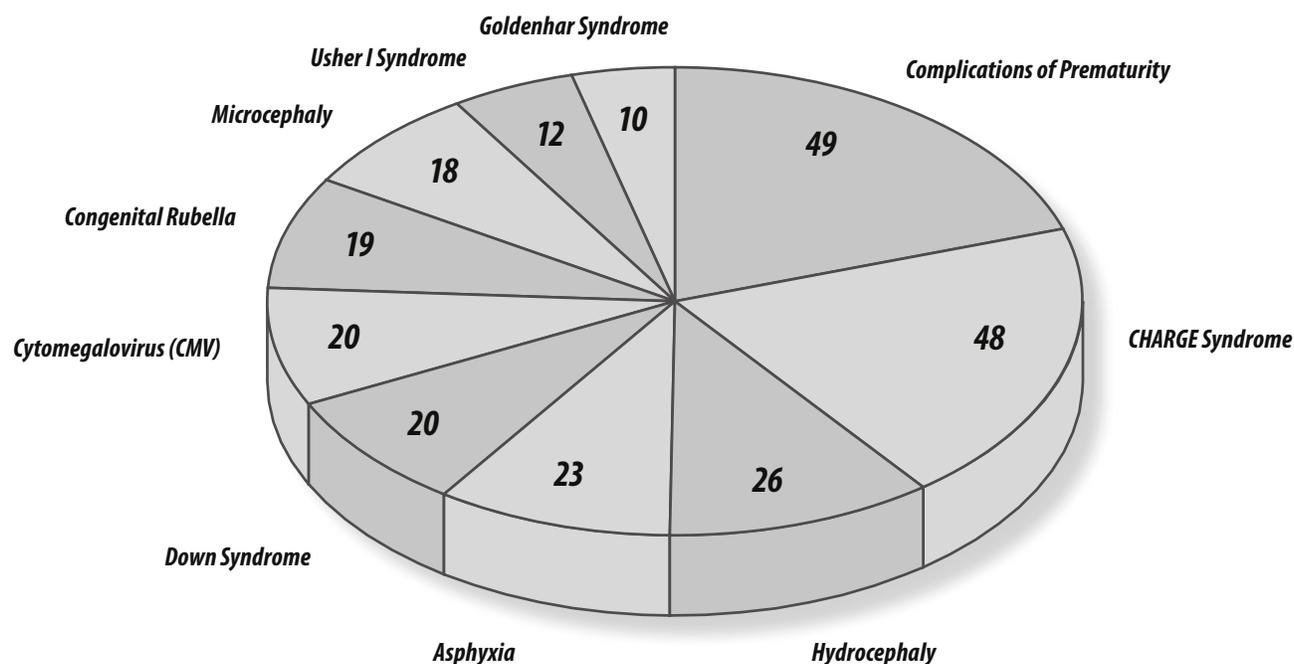
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California's Leading Causes of Deaf-Blindness

CDBS conducts an annual census of all children in California who have combined hearing and vision problems. This information assists the federal government in determining the funding level for CDBS, and the information also provides valuable data for CDBS staff, e.g., program planning, newsletter topics, training topics, etc. In California, the most common designation under the etiology section is "no determination of etiology", meaning the cause of the children's deaf-blindness is unknown. The chart below shows the most common causes of deaf-blindness in California from the 2002 census, not including the "unknown" and "other" categories.

Top Ten Causes

number of children per etiology



Fact Sheet

Points to Consider About Etiologies

by Maurice Belote, CDBS Project Coordinator

Etiology simply means the cause of a child's medical or disability condition. Etiologies of deaf-blindness can be hereditary/chromosomal syndromes and disorders such as Down syndrome, pre-natal/congenital complication such as fetal alcohol syndrome, post-natal complications such as asphyxia or meningitis, and complications as a result of prematurity. For some children, the cause of their combined vision and hearing problems is unknown, and other children have more than one etiology. To have an accurate diagnosis of a child's deaf-blindness may answer many troubling questions, or it may raise more questions than it answers. The following are a few considerations about etiologies that may be helpful.

- Professionals need to gather as much information about the cause of a child's deaf-blindness as possible prior to establishing an intervention or educational program. This information will be very useful in understanding many areas of the child's development, such as fine and gross motor skills, social/emotional development, language acquisition, and development of the vestibular system, to name a few. With that said, however, it is also true that...
- To know a child's etiology is not to say that you know the child. Every child is unique, and many etiologies present skills and levels of disability across a broad spectrum.
- For some families in which there is no known cause of their children's deaf-blindness (and other disabilities), this absence of a diagnosis can be a nagging mystery that may affect these parents' well being. The lack of a diagnosis might cause parents to question whether or not to have more children, or might cause them to worry about future generations, i.e., the children of their other sons and daughters.
- Professionals should keep in mind the importance families may place on even casual comments about etiology. A casual mention of a possible etiology might send some families running to the library or Internet to conduct research, and they could very well be unnecessarily frightened by information gleaned.
- Find out if there are delayed manifestations of a child's etiology, such as health problems that develop later in life. For example, excessive thirst by someone with congenital rubella syndrome might be an indicator of a late onset medical condition.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals with dual sensory impairments. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

- Pay attention to the publication date of print and Internet resources. The speed at which current research is adding to what we know about many conditions is fast, and information may be out-of-date within months, not just years.
- Be aware that some information available on etiologies may not be factual. This is especially true of information found on the Internet. Before accepting information as fact, consider the reputation of the organization that produced the material, the source of the information, the process used for gathering and interpreting the information, etc. A resource might include stories of one person's experience, and while these might be interesting and helpful, the information presented may not apply to others with the same diagnosis.
- The value of connecting with another person who shares the same diagnosis cannot be overstated. This is true whether the connection is parent-to-parent, child-to-child, sibling-to-sibling, or grandparent-to-grandparent. Families hear the phrases "I know how you feel" and "I know what you're going through" fairly often, but to speak to someone who truly knows how they feel or what they're going through can be one of the most powerful sources of support, information, and encouragement.

Hoja de Datos

Puntos para Considerar Acerca de las Etiologías

por Maurice Belote, Coordinador del Proyecto CDBS

La etiología solamente significa la causa medica o la condición de la discapacidad del niño. La etiología de la sordo-ceguera puede ser hereditaria/síndrome de cromosoma y trastornos, tales como el Síndrome de Down; complicaciones prenatales congénitas, tales como el Síndrome Fetal de Alcohol; complicaciones postnatales, tales como asfixia o meningitis, y complicaciones del resultado de lo prematuro del bebé. Para algunos niños, la causa de los problemas de visión y auditivos es desconocida, y otros niños tienen más de una etiología. El tener un diagnóstico exacto de la sordo-ceguera del niño pudiera contestar muchas interrogantes, o pudieran resaltar más preguntas de las que se pudiesen contestar. Las siguientes son algunas consideraciones sobre las etiologías que le pudieran ser útiles.

- Los profesionales necesitan recopilar la información que más sea posible sobre la causa de la sordo-ceguera del niño antes de establecer algún programa de intervención temprana. Esta información será muy útil para entender muchas áreas del desarrollo del niño, tales como las habilidades de motor finas y gruesas, las del desarrollo social/emocional, las del desarrollo del sistema vestibular, por mencionar algunos. Habiendo dicho esto, sin embargo, también es cierto que...
- Para saber la etiología del niño, no quiere decir que usted conoce al niño. Cada niño es único, y muchas de las etiologías presentan habilidades y niveles de discapacidad a través de un amplio espectro.
- Para algunas familias las cuales desconocen la causa de la sordo-ceguera de su niño (y de otras discapacidades) la ausencia de un diagnóstico puede ser un misterio que molesta y esto pudiera afectar el bienestar de los padres. La falta del diagnóstico puede causar que los padres se pregunten si quieren tener más hijos o pudiera preocuparlos acerca de futuras generaciones, por ejemplo, los hijos de sus otros hijos e hijas.
- Los profesionales deberían tomar en cuenta la importancia que ponen los padres a cualquier mínimo comentario hecho acerca de la etiología. Cualquier mención de una posible etiología, podría mandar a los padres corriendo a la biblioteca o al internet para investigar sobre eso, y asustarse innecesariamente de la información obtenida.
- Descubra si hay manifestaciones retrasadas de la etiología del niño, tales como problemas de salud que se desarrollan mas adelante en la vida. Por ejemplo, la sed excesiva de alguien con el Síndrome de Sarampión (Rubella Syndrome) pudiera ser un indicador de una condición medica retrasada.

Las hojas de datos de Servicios Para Sordos-Ciegos de California son para ser usadas por ambos familias y profesionales que ayudan a individuos que tienen dos sentidos incapacitados. La información aplica a estudiantes 0-22 años de edad. El propósito de la hoja de datos es para dar información general sobre un tema específico. La información más específica para un estudiante individual puede proveerse mediante la asistencia técnica individualizada disponible desde CDBS. La hoja de datos es un punto para comenzar una información adicional.

- Ponga atención de la fecha que se imprimieron las publicaciones y los recursos por la internet. La velocidad con la que las investigaciones se van añadiendo a lo que ya se sabe sobre muchas condiciones es muy rápida y la información se va haciendo vieja en solo meses y no solo en años.
- Tome en cuenta que la información que esta disponible sobre las etiologías puede que no sea verdadera. Esto es especialmente cierto en información que se encuentra en la internet. Antes de que usted tome la información como verdadera, debe considerar la reputación de la organización o agencia que produjo dicha información, el proceso que se usó para reunir e interpretarla, etc. Uno de los recursos pudiera incluir la historia de la experiencia de alguna persona, y mientras esto sea interesante y útil para unos, puede ser que esta información nos aplique para otras personas con el mismo diagnóstico.
- El valor de conectar con otra persona que comparta el mismo diagnóstico no debe de exagerarse. Esto es verdad aún si ésta conexión es de padre a padre, hijo a hijo, hermano a hermano, o abuelo a abuela. Las familias suelen oír bastante a menudo la frase “yo se lo que sientes” y “yo se por lo que estas pasando”, pero el hablar con alguien quién realmente sabe lo que se siente y por lo que se esta pasando puede ser una de las fuentes de apoyo mas grandes de información y de estímulo.

Is Knowing My Son's Etiology Really That Important?

by Myrna Medina, CDBS Family Specialist

When Norman was born, my husband and I—and even the doctor—thought we were bringing home a healthy 6 lb. 5 oz. baby boy, but reality was different. After a couple of months, we started noticing something different about Norman that we did not see when Deloris, our older daughter, was his age. Something was not normal.

The first thing we noticed that was wrong was his eyesight—his eyes were perfectly normal looking but were not focusing. Sure enough, he was diagnosed to be blind, with an eye condition called Leber's Amorousis. My husband and I were given all the relevant information.

Secondly, after various evaluations Norman was also diagnosed with hypotonia and hypertonia, more "hypo" than "hyper" due to his very low muscle tone.

Thirdly, we discovered that Norman could not hear, and after several tests he was diagnosed with deafness. With this new finding came a new diagnosis: Usher Syndrome. (But Usher Syndrome was eventually ruled out, so we were back to no known etiology of Norman's deaf-blindness.)

Recently, Norman has developed a heart condition and has now been added the diagnosis of dilated cardiomyopathy.

Norman is now 7 years old with multiple disabilities. Sometimes I think back to when he was born, and how we thought he was a perfect, healthy, baby boy.

As time went by and my husband and I were receiving information for each and every diagnosis, it was like they were

taking our baby to pieces. I remember meeting a mom one time, and she told us that the more diagnoses a child has, the more services he gets. But services were not an issue at that time; all we wanted was for the doctors to stop finding more disabilities with Norman. It came to the point where we were afraid to attend doctors' appointments on the chance they would again find something wrong.

There is no doubt that my husband and I found it emotionally difficult to deal with all of Norman's diagnoses. For years we saw Norman as a boy with no vision, no hearing, a boy who couldn't walk or even sit up by himself, and with a severe heart problem. Every time we talked about him, his diagnoses came up first in the conversation.

So Norman is one of the many children for whom a diagnosed etiology is and might always be a mystery. One day I asked myself: is having a diagnosed etiology for my son really important for my family and me? I discovered that for me a diagnosed etiology is just a label that will not change Norman. He will be Norman forever, even if he has three or four labels. He will continue to be Norman—the happy boy I met the day he was born. I have come to realize that sometimes a diagnosis can, in some ways, limit the way you look at your own children, and how these diagnoses might impact the way others see them and treat them.

I am so thankful that I now see Norman's disabilities in a different perspective. This allows me and my entire family to enjoy ourselves more.

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A Big Thank You

As CDBS comes to the end of another funding cycle, we would like to acknowledge and thank the dedicated members of the CDBS Advisory Committee. The Advisory Committee supports CDBS by suggesting improvements to our service delivery system; informing staff and others of news, trends, and effective and emerging practices; and in supporting collaboration between CDBS and other local, regional, and statewide programs. The following individuals have served during the 1999–2003 funding period:

Shawn Barnard, Technical Assistance Specialist
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San Diego State University

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Exceptional Family Resource Center, San Diego

Deb D'Luna, Parent
Irvine (Orange County)

Dr. June Downing, Professor
California State University, Northridge

Colleen Gaither, Manager
California Department of Rehabilitation, Granada Hills
(Los Angeles)

Dr. Ann Halvorsen, Professor
California State University, Hayward

Jeri Hart, Home Counselor
Off To A Good Start Program of the Blind Babies Foundation,
San Francisco

Dr. Dennis Kelleher, Low Incidence Program Consultant
California Department of Education,
Special Education Division, Sacramento

Cathy Kirscher, Southwestern Regional Representative
Helen Keller National Center, San Diego

Agnes Lopez, Early Intervention Specialist
Bakersfield City Schools

Pat Mejia, Program Director
Support for Families, San Francisco

Cathy Mouchka, Consumer
Sacramento

Tom Neary, Program Specialist
Sacramento County Office of Education

Charlene Okamoto, Program Coordinator
Oakland Unified School District

Pearl Veasart, Region 9 Director
National Family Association of the Deaf-Blind, Los Osos
(San Luis Obispo County)

Joni Young, Case Manager
Golden Gate Regional Center, Corte Madera (Marin County)

Two Excellent New Resources

The following new resource has just been published by Hope, Inc. <www.hopepubl.com> and is a welcome addition to the small but steadily growing list of print materials specific to children who are deaf-blind. The manual is divided into two volumes contained in two 3-ring binders, and chapters are authored by many of the current leaders in the field of deaf-blindness. Each chapter is clearly written and includes useful strategies and points to remember. This is an excellent resource for any program serving children who are deaf-blind.

Understanding Deafblindness: Issues, Perspectives, and Strategies

Editor: Linda Alsop, M.Ed., SKI-HI Institute, Utah State University

Topics covered in Volume I: Introduction, Psychosocial Aspects, Concept Development, Intervention, Vision, Hearing, Touch, Sensory Integration, Neurological Issues/Health, Communication Basics, Early Communication, Communication: Interactive Relationships, Calendar Systems, van Dijk Perspectives.

Topics covered in Volume II: Family Issues, Self-Determination, Behavior, Gross Motor, Fine Motor and Play, Orientation and Mobility: Infants and Young Children, Orientation and Mobility: Adolescents and Young Adults, Daily Care and Self Help, IFSP/IEP, Physical Activity—Physical Education, Sport, and Recreation, Social/Sexual Education, Transition, Community Support.

HomeTalk is an easy to use 42-page assessment tool for families and care providers of children who are deaf-blind, and is designed to assist families in planning their children's education programs. HomeTalk provides a tool for gathering relevant information in one place, and the scoring system leads to goals and activities that can then be integrated into IEPs. The introduction lists four main uses of HomeTalk:

- help develop an IEP
- review a child's progress and needs at a school meeting
- introduce a child to new staff members
- summarize important information about a child.

HomeTalk: A Family Assessment of Children who are Deafblind

developed by the Bringing It All Back Home Project

a collaborative effort of

Design to Learn Projects, Oregon Institute on Disability & Development, Oregon Health & Science University, Portland, and College of Physicians and Surgeons, Columbia University, New York

Information about ordering HomeTalk is available from DB-LINK <www.tr.wou.edu/dblink>.

Educational Assessments Available

by the California School for the Blind Assessment Center Staff

The Assessment Program at the California School for the Blind (CSB) welcomes referrals for students who are deaf-blind. The CSB Assessment Program was created as an outreach agency for the entire state of California. The CSB Assessment Program has collaborated with California Deaf-Blind Services in the past and plans to do more in the future.

The CSB Assessment Program offers observation and consultation in the student's home and school, with recommendations for educational programming tailored to the needs of the child and the family. The observation/consultation model is particularly effective when a child's skills might best be seen in a familiar environment.

Students, who have skills which might be transferable to another location, may be seen with their parents or caregivers at the California School for the Blind Assessment Center for a week long assessment that includes the areas of cognition, emotional and social development, language and communication, functional vision, reading media, academic skills, technology and orientation and mobility.

Assessment services are provided by the California School for the Blind to help school districts serve students as effectively as possible. They are not part of a referral for enrollment at the California School for the Blind. CSB assessment services are not designed to replace assessment from local districts. They are available when local resources have been exhausted, and questions still remain about the best way to provide a school program for a child who is blind or visually impaired.

Teachers and parents can request workshops and training from the Assessment Program. Teachers are welcome to arrange a week-long visit at the California School for the Blind to observe the assessment team in action, and team members are available to travel to districts throughout California to consult on a variety of topics. Past workshops have focused on specific eye conditions, on beginning Braille skills and on assessment of students who are blind or visually impaired by psychologists, speech and language pathologists, professionals who are not specifically trained to work with children who are blind or visually impaired.

The Technology Program at the California School for the Blind is available to assess students' technology needs at their home schools and to train teachers and students in their own districts to use technology, such as Braille note takers and computer programs which are designed for students who are blind or visually impaired.

If you are interested in accessing the services of the Assessment Program or the Technology Program at the California School for the Blind, please call (510) 794-3800. Rich Russo, extension 220, is the director of the Assessment Program. Joan Anderson, extension 237, and Jim Carreon, extension 312, provide the technology assessments and training.

[This information is provided as a service to one of the CDBS partners in service delivery.]

Mark Your Calendar!



Aparte el día -

El Proyecto SALUTE en colaboración con Los Servicios de Sordo-Ciegos de California presentan **dos talleres conducidos en Español para las familias Hispano Parlantes**

Tocando Alrededor: Comunicación táctil con niños que tienen discapacidad múltiple y/o sordo-ceguera

Cuándo y Dónde -

El Sur de California
(Área de Los Angeles)
28 de Junio del 2003

El Norte de California
(Área de la Bahía de SF)
16 de Agosto del 2003

Los padres aprenderán

- a como comunicarse con sus hijos más efectivamente a través del tacto
- a como animar la comunicación expresiva de sus hijos

Si tiene alguna pregunta o le gustaría recibir la solicitud para registrarse, por favor de comunicarse con Gloria Rodriguez-Gil o con Myrna Medina al teléfono 800-822-7884 (voz/TTY), o gloria.gil@gte.net o mmedina46@earthlink.net.

Save the date -

Project SALUTE in collaboration with California Deaf-Blind Services present **two workshops conducted in Spanish for Spanish speaking families**

Reach out and Touch: Tactile communication with children who have multiple disabilities and/or deaf-blindness

Where and When -

Southern California
(Los Angeles area)
June 28, 2003

Northern California
(SF Bay area)
August 16, 2003

Parents will learn

- how to communicate with their children more effectively through touch
- how to encourage their children's expressive communication

If you have questions or would like to receive registration materials, please contact Gloria Rodriguez-Gil or Myrna Medina at 800-822-7884 (voice/TTY) or by email at gloria.gil@gte.net or mmedina46@earthlink.net.



Upcoming COPE D-B Picnics!

Coalition of Parents and Educators Deaf-Blind



June 21, 2003

Earl Baum Center of the Blind
Sonoma

August 23, 2003

Foundation for the Jr. Blind
Los Angeles

September 13, 2003

Rio Bravo Resort
Bakersfield

Contact Myrna Medina or Jackie Kenley at 800-822-7884 (Voice/TTY) for further information.

California Deaf-Blind Services

reSources

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California Deaf-Blind Services

Staff

(800) 822-7884 Voice/TTY

Maurice Belote..... Project Coordinator
David Brown Educational Specialist
Barbara Franklin, Ph.D.Principal Investigator
Lori Goetz, Ph.D.....Project Director
Jackie Kenley Family Specialist
Myrna Medina Family Specialist
Rebecca Randall Information Technology
Larry Rhodes Educational Specialist
Gloria Rodriguez-Gil Educational Specialist

5016 Mission Street
San Francisco, CA 94112
(415) 239-8089 Voice/TTY
(415) 239-0106 Fax
www.sfsu.edu/~cadbs

San Francisco State University
Special Education Department
1600 Holloway Avenue
San Francisco, CA 94132

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