

Volume 10, Number 9 Winter 2001

# Follow the Child – Approaches to Assessing the Functional Vision and Hearing of Young Children with Congenital Deaf-Blindness

by David Brown CDBS Educational Specialist

Talifornia Deaf-Blind Services (CDBS) serves a population of children and young people that covers a very wide spectrum of ability and disability. Even within the group who were born deafblind there is a huge variation in the severity and type of vision and hearing impairments, and many children have neurological damage that results in cortical visual impairment and central auditory dysfunction even though their eyes and ears appear to be intact and working. Increasingly these children have many other problems alongside those associated only with vision and hearing. Severe orthopedic impairments, seizure disorders, heart defects, and breathing and swallowing difficulties are becoming more common, and many of these children also exhibit other sensory problems that affect the touch, taste, smell, movement, balance, and pressure senses. Because of this broad and complex spectrum of difficulties, it is very likely that some of a child's sensory problems will go undiagnosed and unsuspected, and the significance and implications of the sensory problems, both individually and as a whole, will be overlooked in favor of a "global delay" view of the child.

These children present formidable challenges for assessment, and working with them often seems to produce no clear-cut answers but many paradoxes and contradictions:

 Good, up-to-date clinical assessment information is crucially important but this information is often bewilderingly at odds with the child's observed functioning; children who should not be able to see or hear may do either or both of those things surprisingly well—yet those for whom the visual and auditory prognosis seems very good may not appear to see or hear at all.

- A classic "hands-on" approach may seem to be essential to guide and direct the child, but for many children in this population—for a considerable time—"hands-off" may be the only approach which is acceptable.
- A distraction-free environment is essential for successful assessment, yet many of these children function and learn much better when there is a comforting and familiar "buzz" of background noise or movement.
- Children should be assessed when they are well rested and alert, yet sometimes an assessment may be much more successful if the child is quiet, or even very tired when their sensory priorities have altered.
- Standardized assessment procedures assume adult direction in carefully planned and controlled situations, but many children respond very negatively to this kind of direction and control and underfunction as a result.

(continued on page 2)

There is increasing awareness that even children with the most profound disabilities may have usable vision and hearing that they can be helped to use more effectively, and, given the limitations of clinical assessment approaches, more emphasis is being placed upon family members, early intervention and school staff as potential assessors. Even so, for these people lack of success often results from trying to copy aspects of standardized clinical assessment procedures that may be inappropriate and counter-productive. Examples of these include:

- Insisting that the child is sitting upright for the assessment regardless of their postural preferences;
- Using specific, standardized materials for the assessment which may be of no interest at all to the child;
- Setting too brief and inflexible a timescale for the activity—the adult's timescale rather than the child's;
- Eliminating most or all of the play element because of the "serious" nature of the activity;
- Approaching the activity with predetermined ideas about what the child must do in order to be considered to have succeeded.

Basing the assessment approach on the child's curiosity and personal satisfaction, on current abilities and interests rather than on current deficits, on function rather than on structure, on motivated behavior rather than on sterile performance, is now seen as a legitimate and effective way of beginning the process. The approach needs to be individualized and holistic, so that every aspect of the child is taken into consideration even if only one sensory or skill area is being assessed. The emotional needs of the children will exert a direct and powerful influence on their ability to function, so that serious consideration of questions like "How do you feel?" "What do you like?" and "What do you want?" will provide the best basis for successful assessment. People often think that "What can you do?" is the key question to pose to any child during an assessment, but with this group a better question to begin with would be "What do you do?"

When assessing visual and auditory responses in this population it is important to know about the development of vision and hearing skills, and the possible implications of clinical findings. It may also be important to know about the implications for vision and hearing of other conditions like cerebral palsy and epilepsy (CDBS staff can help with all this). General suggestions that can prove helpful include the following:

#### Consult those who know the child better than you or who have a distinctly different viewpoint

Initially it may be helpful to spend a considerable amount of "assessment" time in interviews with family members, early intervention/school staff, etc. in order to gain insights. It is a good idea to organize your questions to make certain that everything is covered. People who know the child well may not realize how much they know nor how important it is, so the interview can serve the extra and very valuable purpose of making them more aware of the insights they already have, where previously they may have been feeling very de-skilled. It is important to record that information gained in this way has not been verified through direct observation, and also to remember that the people being interviewed may not say exactly what they mean, so that careful interpretation and further questioning will be needed.

#### **Identify motivators**

This information may be gained from the initial interviews, but it should also be a goal of the first part of the assessment itself, so the motivators identified can then be used in more specific contexts for further assessment. It is important to consider all possible motivators for the child, not just those concerning vision or hearing.

### Match several different sensory inputs if necessary

This approach must be noted in the assessment record, but it can be a very effective way of alerting a child to use their vision or hearing. One very effective idea might be to use vibro-tactile input, for example on a resonance board, to gain the child's visual and/or auditory attention, or to use a purely visual or auditory signal to indicate that some vibro-tactile stimulation is coming. After a period of time it might be possible to

(continued on page 3)

remove the vibro-tactile input and observe purely visual or auditory responses from the child.

#### Relax or arouse the child

Many of the children in this population are generally very unresponsive to stimuli of all sorts and may need to be carefully aroused into a higher level of alertness to function at optimal level in a visual or auditory assessment. Arousal may be achieved through the careful use of activities involving vibro-tactile input, large rhythmic movements, or stimulating massage, for example. Other children may be over-reacting to certain stimuli and may benefit from activities that encourage relaxation such as a major reduction in environmental stimuli, a hydrotherapy session, or a relaxation massage. Only knowledge of each individual child, and close and careful observation, will enable the effective approaches to be identified on any particular day. By following this principle it may be possible to obtain stronger and more consistent visual and/or auditory responses from some children. A sensory integration dysfunction assessment by a specially trained Occupational Therapist is usually very pertinent to all the children in this population. Some children, when they are feeling alert and full of energy, will be very visual in their behaviors as they explore their surroundings and "turn off" their residual hearing, but when they are too tired to be looking and moving around they may be more receptive to sounds and show surprisingly good auditory behaviors. Observing for these things and then carefully choosing times and environments for the assessment may make a big difference to a child's ability to concentrate on one particular sense.

#### Position the child to facilitate function

Sitting is not the only position in which we can and do use our vision and hearing, and for many of these children it is the least likely position in which they will use their eyes and ears. For children who have problems with balance, postural control, head control, or motor coordination, being supported in the upright position may mean that they have to attend to other urgent considerations rather than to information coming in through their eyes and ears. Only by tackling and minimizing these other considerations can we ever liberate them to concentrate on what they can see or hear. For some children, for example, being placed flat on their back may enable much better visual and auditory functioning, while for others this could be too difficult and challenging a position. Again, each child will have different

needs at different times on different days and at different stages in their development.

## Allow the time necessary for the child to perceive the stimulus and respond

These children operate on a much more extended timescale than ours, and everything they do requires more time, energy, attention, and concentration than it does for us. Using vision and hearing is a very complex and sophisticated process, and each stage in this process (being aware that there is something to see or hear, attending to it and locating it, recognizing and attaching meaning to it, and then responding to it in some planned way) may need a considerable amount of time. Many of these children have never been allowed the necessary length of time to work through this whole process. As with everything else it is important to make a note in the assessment findings of the length of time it took the child to alert, attend, locate, or whatever.

#### Observe for any changes in behavior

It should also be remembered that there are all sorts of ways to respond to a visual or auditory stimulus apart from turning quickly and appropriately, which is often the only behavior that people look for when they are "assessing" a child's functional vision and hearing. Many children may not turn and look but will show that they are aware of the stimulus by changing their breathing rate, or the tone of their muscles, or the rate at which they suck rhythmically on their pacifier, or the types of vocalizations they are making, or any one of many other changes in their behavior. Sometimes these changes may take a while to happen after the flashlight has been turned on or the music box has started to play or whatever, and sometimes the change in behavior will come only after the flashlight has gone out or the music has stopped. These responses may also occur only once or twice in any one session and the child will then seem to stop seeing or hearing until a considerable period of time has passed.

By following these suggestions it is usually possible to begin the difficult process of working out just what a child can see and hear, and how they see and hear. Recording what happened, and looking for consistent patterns of response even within the child's apparently inconsistent behaviors, may be of great help to clinicians in piecing together the assessment jig-saw pattern.

38

## The 2001 California Deaf-Blind Census: Answers To Our Most Frequently Asked Questions

In an effort to make the completion of this year's census of individuals with combined hearing and vision problems as clear and simple as possible, the following questions and answers may be helpful.

- 1. What is the census of children who are deaf-blind? California Deaf-Blind Services (CDBS) conducts an annual count of all children from birth to age 21 in California who have both hearing and vision problems. Although CDBS field staff adds to the census throughout the year, the annual mailing to schools and programs occurs in mid-March and forms are due back to CDBS around mid-May. Because the information on the census is confidential, only specific data is submitted to the federal government (such as cause of deaf-blindness and type of school placement), not student or parent names, home addresses, etc. And although at first glance the form looks daunting, it should only take a few minutes per student to complete.
- 2. Why is the census so important? The census is important for many reasons. Funding for specialized services to this population is dependent on having accurate information about how many infants, children and youth in California have both hearing and vision problems. When the state and national legislatures approve funding—and state and federal agencies allocate the funds—census information is used to determine priorities and needs.
- 3. What exactly is meant by the term "deaf-blind"? CDBS recognizes that this is a difficult question for families and educators, and that the federal definition can be confusing. To make it more clear, CDBS uses a functional definition of deaf-blindness: If an individual (birth through age 21) has combined hearing and vision problems that are significant enough to require considerations (such as specialized adaptations, modifications, and strategies) when presenting information or interacting with the child, then CDBS considers that child eligible to be included on the census and receive services from our project.
- 4. What if a child has multiple disabilities that happen to include vision and hearing problems? Most children who are deaf-blind have additional disabilities, including cognitive disabilities,

- orthopedic impairments, serious health impairments, etc. Please complete a census form for all students that have hearing and vision problems, regardless of the presence or absence of additional disabilities.
- 5. What if the hearing and/or vision problems are cortical in nature? CDBS requests that you include children with sensory impairments that are cortical in nature, such as cortical visual impairment and/or central auditory processing disorder, on the census. These students usually require adaptations and modifications to their programs in order for them to succeed. In addition, the hearing and vision problems often need to be considered when developing effective, formal communication for these individuals. When in doubt, refer to the functional definition of deaf-blindness in question #3 above.
- 6. What if deaf-blindness is not listed as a student's primary handicapping condition on her or his IEP? It doesn't matter which primary handicapping condition is identified on the IEP. While California Deaf-Blind Services would like to see all students who have vision and hearing problems identified as deaf-blind on the IEP (and there are federal regulations regarding this issue), we know that most students in California who are deaf-blind are identified under other federal/state primary disability categories, such as "mental retardation", "multi-disabled", "hearing impaired", "visually impaired", "severely handicapped", etc.
- 7. Does a child have to meet my district's/LEA's criteria for vision and hearing impairment to be included on the census? No. Eligibility for vision and hearing impairment and/or services varies from district to district, and the definitions are interpreted in many different ways. For example, students with only a mild hearing loss and vision loss can be included in the deaf-blind census count since a combined mild loss of both senses can create an adverse effect on educational success. In addition, students who are deaf-blind do not have to meet state criteria since the deaf-blind census and the state count are separate entities (the state count being the number of students in California for whom deaf-blindness is marked on the IEP as the primary handicapping condition).

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#### **Deaf-Blind Census (continued from page 4)**

- 8. Does including a child on the census obligate the school program to provide services such as vision, hearing, orientation and mobility, etc.? No. Individualized needs and services are determined by the family and educators through the IEP or IFSP process.
- 9. Why is a child's etiology included on the census? Knowing a child's etiology is important for a number of reasons. Having this database allows CDBS staff to make important connections between families. For example, parents of a child with Cockayne Syndrome might contact CDBS and ask if there are other parents of children with the same syndrome in their area. The census allows CDBS to make these family-to-family connections. Another important reason to know etiology is that the California census information is combined with data from around the country to determine which causes of deaf-blindness are on the increase or decrease, if there are geographic clusters of students with similar etiologies, etc.
- 10. What if my district/county/SELPA does not currently have any deaf-blind students at this time? It is possible that smaller Local Education Agencies may not have any students with combined hearing and vision problems. Statistically, we know that there should be about one child who is deaf-blind for every 4,200 students in a district. Another guide we use is that there are approximately 2 students who are deaf-blind for every 1,000 receiving special education services. CDBS field staff is available to assist you in your identification efforts.
- 11. What if I don't know all the information requested on the census form for a particular student? Give us as much information as you have. Don't worry if you are missing some information, such as the date of the student's last vision exam. It is more important to CDBS that we have an accurate count of students, and the missing information can be added in subsequent year's counts.
- **12.** Who should complete the census form? Anyone can complete the census form, including educators, school health personnel, family members, and/or CDBS staff.
- **13.** What if I have a question about the census that hasn't been answered here? Please contact Maurice Belote at mbelote@pacbell.net or by telephone toll-free at 1-800-822-7884 ext. 23 (voice/TTY).

**Our team** is here to serve families and professionals of individuals who are deaf-blind, birth through age 21. Please get in touch with us if you have questions or feel we could be of assistance!

How to access our services (800) 822-7884 Voice/TTY

Jackie Kenley, Family Specialist, ext. 21
Myrna Medina, Family Specialist, ext. 25
Gloria Rodriguez-Gil, Educational Specialist, ext. 26
Larry Rhodes, Educational Specialist, ext. 24
David Brown, Educational Specialist, ext. 22
Maurice Belote, Project Coordinator, ext. 23

### Help keep us up-to-date!

Email us at cadbs@sfsu.edu with changes to our mailing list, or fill out this form and mail (or fax 415-239-0106) it to:

CDBS reSources
5016 Mission Street
San Francisco, CA 94112

Name Title/Affiliation Address				
				<ul> <li>Add me to your mailing list.</li> <li>Note change of address.</li> <li>I would prefer to receive my issue in Spanish.</li> </ul>

## **Check it out!!!**

California Deaf-Blind Services has added some exciting books to the lending library that you might like to have a look at:

Building Inclusive Schools: Tools and Strategies for Success by Ann T. Halvorsen and Thomas Neary. Boston: Allyn and Bacon, 2001. 226 pages.

Learning to Listen: Positive Approaches and People with Difficult Behavior by Herbert Lovett. Baltimore: Paul H. Brookes Publishing Co., 1996. 269 pages.

A Guide to Planning and Support for Individuals who are Deafblind edited by John M McInnes. Toronto: University of Toronto Press, 1999. 554 pages.

Remarkable Conversations: A Guide to Developing Meaningful Communication With Children and Young Adults Who Are Deafblind edited by Barbara Miles and Marianne Riggio.



Watertown: Perkins School for the Blind, 1999. 310 pages.

Educating Students who have Visual Impairments with Other Disabilities edited by Sharon Sacks and Rosanne Silberman. Baltimore: Paul H. Brookes Publishing Co, 1998. 519 pages.

....and two videocassettes:

Oh, I See!: A Lively Introduction to What Having a Visual Impairment

Means and How Elementary and High School Students With Visual Impairments Function in School Settings by Carolynn Longuil. New York: American Foundation for the Blind. 9 minutes.

You and Me: A Five Part Video Series About Educating Children Who Are Deaf-blind. Volume 4 – Social Connections. Monmouth: Teaching Research Division, Western Oregon University, 1997.



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## Fact Sheet

## Considerations when Assessing Children and Youth of Spanish Speaking Families

The following are recommendations to consider when conducting an assessment on a child or youth of a Spanish speaking family that does not fluently speak English.

- 1. At the start of the assessment, it is important to provide the parents with basic information about yourself and any other professionals participating in or observing the assessment. This information should include your name, the name of your agency, the purpose of the assessment, and the nature of the assessment. It is important to provide parents with a clear and concise explanation of your work with the child so they can feel respected and comfortable during the assessment.
- 2. If the assessor is not bilingual (Spanish and English), secure a skilled, professional interpreter. This is critical if the child, youth, and/or family is not fluent in English. Not only would the interpreter facilitate the child's/youth's understanding of the assessor, but the parents would be able to follow along and participate, if needed, in the assessment process.
- 3. When an interpreter is used, additional time needs to be allotted for the assessment. This allows for interpreting between languages—particularly if interpreting is not simultaneous. Also, there is not a one-to-one translation between English and Spanish. What may be said in four or five words in one language may require more words when interpreted into the other.
- 4. Give the parents time to process what they hear. Allow them to absorb the meaning. Likewise, wait for the interpreter to finish the idea completely before you resume speaking.
- 5. If there is more than one professional conducting and/or observing the assessment, the interpreter must be allowed to interpret any remarks and conversations between the professionals. It is not prudent for the professionals to trade comments if the comments are not shared with the parents; this could inhibit the parents' trust in the professionals. Parents, regardless of culture, tend to feel anxious when witnessing or participating in an assessment of their children.

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.

- 6. Give special consideration to being concise and clear when speaking to the family. Excessive verbal information can be confusing and/or overwhelming. However, if there is any question regarding the family's comprehension of what is said, it may be helpful to repeat the information in a slightly different manner.
- 7. All professional terms/jargon (e.g., "assessment", "fundus", "intra-ocular", etc.) should be defined for the parents. One effective strategy for this is to prepare, in advance, a list of terms with definitions that has the Spanish translation next to the English definition. As a term is used during the assessment, the assessor can refer the parents to the term and definition with its Spanish translation. Parents may be anxious during the assessment, providing them with the written definitions and Spanish translations might be useful to the parents for review after the assessment is completed.
- 8. Encourage parents to ask questions and make comments during the assessment. Remember that many parents may be embarrassed about asking questions. When an interpreter is involved, the parents may be more reluctant to interrupt and ask questions.
- 9. Have a genuine respect for the family. When an interpreter is used, it is often easy to direct comments and questions to the interpreter rather than to the family. Be mindful to establish and maintain eye contact with the family. Speak directly to the family; do not speak to the interpreter using phrases such as "Tell them (the family)...", "Ask them (the family)...", and so on.
- 10. Consider working in collaboration with the parents. As a professional, you have theoretical and practical knowledge, however, the parents are the ones who know best the child you are assessing. They observe and interact with the child every day.
- 11. The results of the assessment must be in both English and Spanish. Spanish makes the results accessible to parents; English enables parents to share the results with other professionals and service providers.



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## Hoja de Datos

### Consideraciones Para Evaluar Niños Y Jovenes De Familias Hispano-Parlantes

Las siguientes son recomendaciones que considerar cuando se conduce una evaluación en un niño o joven de una familia hispano-parlante que no habla fluidamente el Inglés.

- 1. Al principio de la evaluación es importante proveer a los padres con información básica sobre usted mismo y cualesquier otro profesional que participe en la evaluación. Esta información debería incluir su nombre, el de su agencia, el propósito de la evaluación y la naturaleza de la misma. Es importante proveer a los padres con una explicación clara y concisa de su trabajo con el niño para que se sientan respetados y estén confortables durante la evaluación.
- 2. Si el evaluador no es bilingüe (Español-Inglés) consiga un intérprete profesional calificado. Esto es crítico si el niño, el joven o la familia no hablan Inglés fluidamente. No solamente el intérprete va a facilitar la comprensión del evaluador por parte del niño o el joven, sino que los padres serán capaces de seguir y participar en la evaluación si es requerido.
- 3. Cuando se use un intérprete recuerde de destinar tiempo adicional para la evaluación. Esto permite que el tiempo de traducción sea tomado en cuenta sobre todo si ésta no es simultánea. También recuerde que la traducción entre el Inglés y el Español no tiene correspondencia idéntica, generalmente el Español toma más palabras para decir lo mismo que se dice en Inglés.
- 4. Dele a los padres tiempo para procesar lo que están escuchando. Permítales absorber el significado de lo que se dice. Asimismo, espere a que el intérprete termine la idea completamente antes de que usted siga hablando.
- 5. Si hay más de un profesional conduciendo u observando la evaluación, al intérprete se le debe permitir traducir cualquier comentario o conversacion que se dé entre los profesionales. No es prudente para los profesionales intercambiar comentarios, si éstos no van a ser compartidos con los padres de familia; ésto puede dañar la confianza de los padres hacia los profesionales. Los padres de familia, sin que importe de que cultura provengan, tienden a sentirse ansiosos al presenciar o participar en evaluaciones de sus hijos.

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 especifico. La información más especifica 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.

- 6. Preste cuidado especial a ser conciso y claro cuando hable con la familia. El exceso de información verbal puede ser abrumador o crear confusión. En todo caso, si hay cualquier duda sobre la comprensión por parte de los familiares de lo que se está diciendo, puede ser de ayuda repetir la información de una manera levemente diferente.
- 7. Todos los términos profesionales como "evaluación", "fundus". "intraocular", etc. deben ser definidos para los familiares. Una estrategia efectiva es preparar por adelantado una lista de términos con definiciones que tenga la traducción al Español junto a la definición en Inglés. Conforme un término sea usado durante la evaluación, el evaluador puede referir a los padres a ese documento. Proveer a los familiares con las definiciones escritas y su traduccion servirá además para que ellos los revisen con calma después de que la evaluación se haya efectuado.
- 8. Aliente a los padres a hacer preguntas y comentarios durante la evaluación. Recuerde que muchos familiares se sienten avergonzados de hacer preguntas. Cuando un intérprete está involucrado los familiares pueden presentar resistencia a interrumpir y a hacer preguntas.
- 9. Demuestre consideración y respeto por la familia. Muchas veces cuando se usa un intérprete se tiende a dirigir comentarios y preguntas a él en lugar de a la familia. Trate de establecer y mantener contacto visual con la familia. Hábleles directamente. Evite hablarle al intérprete refiriéndose a la familia con frases como: "pregúnteles...", "dígales...", o frases semejantes.
- 10. Trabaje en colaboración con los padres. Usted tiene el conocimiento teórico y práctico como profesional, pero ellos son los que mejor conocen al niño o joven que está siendo evaluado. Los padres lo observan e interactúan con él cada día.
- 11. Los resultados de la evaluación deben ser proporcionados tanto en Inglés como en Español. El Español hace los resultados accesibles a los familiares, el Inglés les permite compartir los resultados con otros profesionales y proveedores de servicios.

California Deaf-Blind Services Presents An Interactive Satellite Training

### A Place Called Home: Creative Living Options for Individuals who are Deaf-Blind and/or Have Severe Disabilities

Tuesday, May 8, 2001 • 3:00 - 5:00 p.m. Pacific time broadcast from San Francisco State University



**Target Audience:** Family members, Regional Center case workers and supported living coordinators, educators of transition-age students, paraprofessionals/interveners, and all those who know and care about an individual who is nearing the transition from school to adulthood.

**Training Content:** Where will an individual who is deaf-blind live when she or he moves out of the family home and into the outside world? This is one of the most daunting tasks for families, educators, and service providers. There is no need to fear the unknown, however. The two training presenters have many years experience with providing supported living for their own children with severe disabilities, as well as helping many other families and support teams throughout the state and nation to develop creative living options for individuals who require support. This training will provide an overview of creative living options, including parent vendored supported living, as well as individually or agency managed living programs.

Presenters: Joan Schmidt and Kathi Campbell of "homelink".

This is an interactive training. Viewers will have the opportunity to phone in questions to the presenters during the telecast. Participants in the San Francisco area are encouraged to join the studio audience at SFSU. The broadcast will be real-time captioned.

Please contact Maurice Belote at CDBS if you need assistance in locating a downlink site in California. You are welcome to downlink and tape the broadcast, and copy the tape for wider dissemination. CDBS will also have tapes of the telecast available. Please e-mail requests for tapes to cadbs@pacbell.net and include the delivery address and phone number.

Please copy and distribute this flier to all interested individuals. To register for the tra ining, complete the form below and mail/fax/e-mail to CDBS. In-state and out-of-state registration is free, but registration is required to receive downlink technical information. Registrations must be received by April 20, 2001 to guarantee postal arrival of technical information and/or handouts.

cdbs • 5016 Mission Street, San Francisco, CA 94112 phone (415) 239-8089 V/TTY • fax (415) 239-0106 e-mail cadbs@sfsu.edu • http://www.sfsu.edu/~cadbs

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Name				
Address	City	State	Zip	
Daytime phone ( )	Evening phone (	)		
Fax number ( )	E-mail address			
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### California Deaf-Blind Services reSources

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## California Deaf-Blind Services Staff

(800) 822-7884 Voice/TTY

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

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

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

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ADDRESS SERVICE REQUESTED