

Gifts from my Sister (continued from page 1)

It is easy to feel responsible for a sibling with disabilities, especially if you are older than they are. My parents have helped me work through that by explaining that I am not now and never will be the only one responsible for Laura. Although I know I do need to help out with her, I also know that my parents are doing the best that they can to support Laura, even in case something should happen to either of them. Wills and future living situations and dreams for Laura have all been explained to me, so I have never been left worrying whether or not I will be spending my time as an adult caring for Laura. Communication about these real-life, real-world issues has made me feel comfortable about being Laura's sister in the future.

Having Laura as my little sister has undoubtedly changed the way I look at myself and at the rest of the world. It has taught me how not to get embarrassed so easily, how to deal with the unexpected, and how to appreciate the little things in life (like the fact that dinner has not been thrown all over the kitchen for once, or that no one threw a fit in the middle of the shopping mall). But more than that, Laura has taught me that lots of people out there need help (myself often included). Because of Laura I have chosen Sociology as my area of study in college, and have spent spare time volunteering in California and Louisiana. But most importantly, because of Laura I am able to look at life in an extremely positive way and with a sense of humor, and although that may sound cliché it is the truth. Not many people can or ever will be able to appreciate life and its blessings the way that I can and my sister Laura is the person I have to thank for those gifts.

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What are Satellite Trainings?

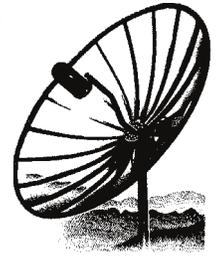


Satellite trainings are interactive workshops that are viewed at downlink sites throughout California. Many school districts, county offices of education, community colleges and universities maintain downlink satellite stations. Some private individuals also have satellite downlink capability. The best way to locate a site is to call the technical support staff at your local school district and/or county office of education. If you work for the district or county, or if you are a family member with a child in the system, the downlink is usually provided free of charge. These same sites may also be willing to downlink the broadcast onto video tape so that you have an instant copy of the broadcast, whether or not you view the broadcast live.

Joining a group of people at a downlink site is a great way to meet others who are interested in the topic, and to make connections for future events. Bring some snacks and sodas, and plan on staying for a while after the broadcast for an informal discussion of the content presented and to share personal stories and strategies.

>> California Deaf-Blind Services Presents An Interactive Satellite Training <<

Growing Up Together: Supporting Siblings of Children who are Deaf-Blind



Thursday, October 24, 2002 • 3:00 – 5:00 p.m. Pacific time
broadcast from San Francisco State University

Target Audience: The primary audience for this training is family members, i.e., parents and other care providers, and those who provide services to families. While the training is not targeted specifically to siblings, older siblings will also likely benefit from either participating as audience members or by viewing at a later date.

Training Content: Sibling relationships are always complex, but are often even more complex when a brother or sister has disabilities including hearing and vision problems. This training will address sibling issues, and identify strategies parents can use to support brothers and sisters. The training will also assist service providers, including special educators and caseworkers, in serving all the members of a family by viewing brothers and sisters as important influences on family dynamics. Topics will include: appreciating typical sibling relationships to better understand what can be expected even when disability isn't a factor; patterns that are seen when sibling relationships are out of balance; understanding normal feelings that occur that may cause emotional issues for siblings; and what parents and care providers can do to help everyone in the family feel special. The training will include video clips of siblings of all ages speaking from the heart about what it is like to have brothers or sisters who are deaf-blind.

Presenter: Cathy Groves, Ph.D.

Dr. Groves is a San Francisco-based clinical psychologist with over 30 years of experience as an educator and psychologist serving children with special needs and their families.

This is an interactive training. Viewers will have the opportunity to phone in questions to Dr. Groves 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 or sign language interpreted.

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 training, 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 October 7, 2002 to guarantee postal arrival of technical information and/or handouts.

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What's Up With COPE D-B?

by Jackie Kenley, CDBS Family Specialist



Did you know that in this very large and diverse state of California, we families of—and teams for—kids who are deaf-blind have an organization called COPE D-B, which stands for Coalition of Parents and Educators Deaf-Blind. This organization has been around since 1991 and has as its goals helping bring members (anyone can be a part) together for recreational activities, for sharing experiences, support and just plain fun. COPE D-B is there for the entire family—siblings especially!

COPE D-B has been awarded a number of annual grants from the Hilton/ Perkins Program of Perkins School for the Blind, Watertown, Massachusetts (the Hilton/Perkins Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada). These Hilton/Perkins grants together with individual donations have, in the past, helped fund family camps and other activities for families of children who are deaf-blind. For the past three years the grants have been used primarily to fund the regional family picnics. Last

year, we held two regional picnics and this year we have had three—Sonoma in June, Los Angeles in August (a huge thank you to the Foundation for the Junior Blind for having us) and Bakersfield in September. Over 70 people joined us in LA, and we had a great turnout in Bakersfield as well. The Sonoma Picnic was our first in northern California, and we know it will grow larger each year.

California Deaf-Blind Services has always been supportive of COPE D-B and the staff members are vital participants in the organization. CDBS realizes that this organization is an integral part of supporting children and families in the state. If you have ideas for future activities or would like to participate in any way with COPE D-B, please contact Myrna Medina, Jackie Kenley or one of the COPE D-B officers. We are grateful to Hilton /Perkins for helping our organization stay afloat!

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CDBS fact sheets and past issues of reSources newsletters



are available online at
www.sfsu.edu/~cadbs

Fact Sheet

Brothers and Sisters: Strategies for Supporting Siblings of Children who are Deaf-Blind

by Jackie Kenley and Myrna Medina, CDBS Family Specialists

Brothers and sisters who have siblings with combined hearing and vision problems are *first of all people and important members of the family*. Siblings will probably want to know why this happened to their brother or sister and how it will affect them personally. This is especially important at the time the family is dealing with a new diagnosis; siblings need to be remembered at these times and have their questions answered and their concerns addressed. It will be helpful for siblings to understand exactly what and how much their sibling may see and hear, and about additional disabilities the sibling may have. Being open and actively listening to siblings may be tough for parents as they deal with a child who is deaf-blind, but these conversations are likely to be as healing for the parents as they are for the siblings.

Things to consider:

Emotional Stages. Learning to live with a child who is deaf-blind requires going through all kinds of emotional stages—anger, grief, sadness, hope and acceptance. To help deal with these emotions, it's a good idea to meet other parents of children with disabilities, share stories with them, and attend family support groups. Many times these various emotions come up at different times for individual family members. Birthdays and holidays are often tough on families, and this should be remembered and worked through as a family. For birthdays, sometimes it is very nice to celebrate each member of the family separately, if financially possible; if not, do not feel guilty about celebrating the siblings in a special way, or siblings might think there is a preference for the child who is deaf-blind.

Take a break! Giving the family a break from the responsibilities of caring for a child who is deaf-blind may be helpful, and provides family members the time to concentrate on other relationships in the family. Respite care or camps are a good idea for parents and siblings. Each child in the family has a need for individual care and attention, and giving this attention may require special effort and energy from parents. It is important for professionals working with the child who is deaf-blind to let the family know that it is *okay* for them to say we are tired, or we need help, and also emphasize that they are there to serve the entire family, not only the child who is deaf-blind.

There are positives as well as negatives. Having a sibling who is deaf-blind can have both positive and negative effects on the family. Different “behaviors”, surgeries, and illnesses are tough on all family

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.

members. For these moments of struggle, the family and friends as well as other people involved need to be united and provide all the support possible. Even time spent just holding hands or giving/receiving hugs can help soothe these moments. On the positive side, the ability to enjoy the accomplishments of a person who is deaf-blind, no matter how big or small, can bring joy to all members of the family. The best way is to “celebrate”, meaning make a big deal out of these accomplishments.

Have a back-up plan. It is important for therapists and teachers to be open to the siblings’ presence and their questions. The most important thing for therapists and teachers to do is to be honest with families, and express if they are okay with the presence of siblings during therapy sessions, knowing that this might be a little disruptive. For parents, it is better if there is another older person in the house who can take the siblings someplace else while the therapy is given, because parents do not want the siblings to have hurt feelings if the professionals are not open to their presence.

Families need all the help they can get. It is necessary for medical professionals and counselors as well as regional center workers and related project personnel to offer each family all the help they can use, and provide all the resources in the community for the entire family and not just for the child who is deaf-blind.

Siblings may feel responsible for their brother or sister who is deaf-blind. These feelings of responsibility may be emotional, and later in life related to financial matters. Families often may not realize the specific concerns that siblings have. To avoid or prevent these future feelings, it is necessary to have conversations with the siblings that address all the important issues and concerns related to the child who is deaf-blind. It is important to give each individual sibling their own space and not overload them with extra responsibilities on top of the ones they already have. It is important to include siblings in planning for the future of the child who is deaf-blind. Using a person-centered planning approach is a good way to focus attention on the individual who is deaf-blind while at the same time including everyone who cares about the individuals’ future in the process.

Younger siblings need special consideration. It is important for parents as well as professionals working with children who are deaf-blind to remember that young siblings might have sensitive feelings that can be easily hurt. To avoid making the siblings feel left out or not wanted, we can make them feel they are important and include them in various activities throughout the day, e.g., bath, play.

We are all unique. Cultural and religious differences may strongly affect the way a family deals with a child with disabilities. Family and individual counseling may be helpful, but each family will likely have their own unique way of dealing with issues related to the child who is deaf-blind, and this needs to be understood and respected by the professionals involved with the family.

Hoja de Datos

Hermanos y Hermanas: Estrategias de Apoyo para los Hermanos y Hermanas de Niños o Niñas que son Sordo-Ciegos

por Jackie Kenley y Myrna Medina, Especialistas Familiares de CDBS

Niños y niñas que tienen hermanos o hermanas con una combinación de problemas tanto auditivos como de la visión, ante todo son personas y forman una parte importante como miembros de la familia. Los hermanos y hermanas probablemente quieran saber porqué le paso ésto a su hermano o hermana y cómo ésto les afectará personalmente. Ésto es importante especialmente en el momento que se está tratando con un nuevo diagnóstico. En esos momentos uno debe de recordarse de ellos, por lo tanto contestarles todas sus preguntas y tratar todas sus preocupaciones. Sería de mucha ayuda para los hermanos y hermanas que entendieran exactamente qué y cuanto pueden ver y escuchar sus hermanos o hermanas, y sobre otras discapacidades que estos pudieran tener. El estar dispuesto y activo a escuchar las cosas que los hermanos y hermanas tienen que decir, pudiera ser muy difícil para los padres, al mismo tiempo que ellos se ocupan de el niño o niña quién es sordo-ciego, pero mas adelante éstas conversaciones muy probablemente sean de sanación tanto para los padres como para los hermanos.

Cosas a considerar:

Estados Emocionales. Aprender a vivir con un niño o niña quién es sordo-ciego, requiere pasar por todo tipo de estados emocionales, coraje, culpabilidad, pena, esperanza y aceptación. Para ayudar a tratar estas emociones, es bueno conocer otros padres de niños con discapacidades, compartir historias y atender grupos de apoyo familiar. Muchas veces éstas varias emociones pudieran resaltar en diferentes momentos por separado para cada miembro de la familia. Los cumpleaños y días festivos son muchas veces difíciles para las familias, ésto se debe de recordar y trabajar entre sí como grupo familiar. Para los cumpleaños, algunas veces es bonito celebrar cada miembro de la familia por separado, si ésto es posible economicamente. Si no, no sentirse culpable si se celebra al hermano o hermana de una manera muy especial, o ellos pudieran pensar que hay preferencia por el niño sordo-ciego.

Tomar un Descanso. Dándole a la familia un descanso de las responsabilidades de cuidar un niño o niña quién está sordo-ciego, puede ser de mucha ayuda y provee a los miembros de la familia tiempo para concentrarse en alguna otra relación familiar. Respiro “respite” o campamentos, pudieran ser de mucha ayuda para los padres y hermanos. Cada niño o niña en la familia necesita cuidado y atención individual, y dar esa atención requiere de un gran esfuerzo y energía por parte de los padres. Es importante para los profesionales que trabajan con el niño o niña que está sordo-ciego, que es normal y está bien que digan que están cansados, o necesitan ayuda, y también enfatizar que están ahí para servir a la familia entera y no solamente a el niño o niña que está sordo-ciego.

Hay Cosas Positivas al Igual que Negativas. El tener un hermano o hermana con sordo-ceguera puede tener efectos positivos y negativos en la familia. Diferentes “comportamientos”, cirugías, y enfermedades son muy difícil

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.

para los miembros de la familia. Para esos momentos difíciles, la familia, las amistades al igual que las personas envueltas necesitan de estar unidas y proveer todo el apoyo que sea posible. Aún solo el tomarse de las manos o dar o recibir un abrazo pudiera suavizar éstos momentos. En lado positivo de esto, la habilidad de disfrutar los logros de una persona quién es sordo-ciega, no importando que tan grande o pequeños éstos sean, puede traer alegría a todos los miembros de la familia. La mejor manera es “celebrar”, esto quiere decir, hacer algo grande de éstos logros.

Tener un Plan de Reserva. Es importante para los terapeutas y maestros estar dispuestos a recibir la presencia y las preguntas de los hermanos o hermanas. Lo más importante para los maestros y terapeutas es el ser honestos con las familias, y expresar si en realidad está bien con ellos que los hermanos o hermanas estén presentes durante la sesión de terapia, sabiendo de antemano que esto puede distraerlos. Para los padres, sería mejor, si hubiese alguna otra persona mayor en la casa quién pudiera llevar al hermano o hermana a alguna otra parte mientras la sesión de terapia, porque los padres no quisieran que sus otros hijos se ofendan si los profesionales no están de acuerdo que estén presentes.

Las familias Necesitan Toda la Ayuda que se les Pueda Dar. Es importante para los doctores y consejeros al igual que los trabajadores del centro regional y algún otro personal, el ofrecerle a cada familia toda la ayuda que ellos puedan usar, y proveerles todos los recursos en la comunidad para toda la familia y no solo para el niño o niña que es sordo-ciego.

Los Hermanos o Hermanas Pueden Sentirse Responsables del Hermano o Hermana Quién es Sordo-Ciego. Éstos sentimientos de responsabilidad pueden ser emocionales, y más tarde en la vida ser relacionados con asuntos financieros. Muchas veces las familias no se dan cuenta de las preocupaciones específicas que los hermanos o hermanas puedan tener. Para evitar y prevenir éstos sentimientos en el futuro, es necesario tener conversaciones con los hermanos para discutir todos los detalles y preocupaciones relacionados con el niño o niña que es sordo-ciego. Es importante darle a los hermanos individualmente su propio espacio y no sobrecargarlos con más responsabilidades de las cuales ellos ya tienen. Sería importante incluir a éstos en la planeación del futuro del niño o niña quién es sordo-ciego. Usando el método de Planeación de Enfoque Personal “Person Centered Planning” es una manera de dirigir la atención al niño o niña quién es sordo-ciego, mientras, al mismo tiempo incluir a todo aquel que se preocupa sobre el futuro del individuo y su proceso.

Los Hermanos y Hermanas Menores Necesitan Consideración Especial. Es importante para los padres al igual que los profesionales que están trabajando con el niño o niña quién es sordo-ciego, que recuerden que los hermanos o hermanas menores pudieran ser muy sensibles y pueden ofenderse con facilidad. Para evitar hacer que los hermanos y hermanas se sientan hechados a un lado o no queridos, los pudieramos hacer sentir importantes e incluirlos en varias actividades durante el día, por ejemplo, durante (el baño o la hora de jugar).

Todos Somos Únicos. Diferencias culturales y religiosas pudieran afectar fuertemente la manera que una familia trata a un niño o niña con discapacidades. Consejería familiar o individual pudiera ser de mucha ayuda, pero cada familia probablemente pudiera tener su propia y única manera de enfrentar éstos problemas relacionados a él niño o niña quién es sordo-ciego, y es necesario que esto se entienda y se respete por parte de los profesionales envueltos con la familia.

Check out the CDBS Library!

The following resources are available free of charge from the CDBS lending library.

Call toll-free 800-822-7884 ext. 23 (voice/TTY) to request these and other materials.



These print and video resources specifically address sibling issues:

Brothers & Sisters – A Special Part of Exceptional Families, by Thomas H. Powell and Peggy Ahrenhold Ogle. Published in 1985 by Paul H. Brookes Publishing Co., Baltimore, Maryland. 182 pages. This is the oldest resource listed here, but it is still an excellent guide that includes strategies for supporting siblings, including keys to effective communication, counseling issues, and considerations for encouraging sibling interaction.

Sibshops: Workshops for Siblings of Children with Special Needs, by Donald J. Meyer and Patricia F. Vadasy. Published in 1994 by Paul H. Brookes Publishing Co., Baltimore, Maryland. 225 pages. This book serves as a guide to everything you need to know to plan and conduct a Sibshop. Sibshops are events held for brothers and sisters of children with disabilities to give siblings the chance to meet other siblings and share common feelings—all in a relaxed, recreational atmosphere.

Views From Our Shoes: Growing Up with a Brother or Sister with Special Needs, edited by Donald Meyer. Published in 1997 by Woodbine House, Inc., Bethesda, Maryland. 113 pages. This book contains short essays written by 45 siblings who have brothers or sisters with disabilities. The writers range in age from four to eighteen years old, and each writes with sensitivity and heartfelt honesty about their experiences. The essays are in order of the age of the writer, from youngest to oldest.

Brothers & Sisters: Growing Up with a Blind Sibling, produced in 1992 by the Institute for Families of Blind Children, Los Angeles. 12 minutes. This informative and touching videotape features brothers and sisters of children who are blind speaking from the heart about their experiences, and includes tips for parents and other siblings.

And here are three more excellent resources for parents that are worth reading:

From the Heart: On Being the Mother of a Child with Special Needs, edited by Jayne D.B. Marsh. Published in 1994 by Woodbine House, Inc., Bethesda, Maryland. 149 pages. This book is a compilation of the reflections, experiences, and words of wisdom from nine mothers who participated in a parent support group process. The book is divided into broad categories, e.g., Being Heard, Coping, Healing, and the stories told in the book were either written for the text or transcribed from the parent support meetings.

I wish...Dreams and Realities of Parenting a Special Needs Child, by Kate Divine McAnaney. Published in 1992 by United Cerebral Palsy Association of California, Inc., Sacramento, California. 86 pages. This short book, written by a parent, begins with 32 “wishes”, e.g., I wish I could stop feeling guilty about my child’s condition, I wish I could get a break from making all these decisions, I wish I could not be so obsessed with my child’s disability. The book ends with 7 wishes from adults with disabilities looking back at their childhood, e.g., I wish people didn’t think of me as disabled, I wish that more parents of disabled children recognized that feeding the soul is just as important as treating the body.

Uncommon Fathers: Reflections on Raising a Child with a Disability, edited by Donald J. Meyer. Published in 1995 by Woodbine House, Inc., Bethesda, Maryland. 206 pages. This book is a compilation of 19 essays written by fathers of children with disabilities. The essays are in order of the age of the writers’ children, from the youngest (age 4) to the oldest (age 28), and share the writers’ feelings, emotions, and dreams.

California Deaf-Blind Services

reSources

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