

The Impact of Having a Child Who is Deafblind on the Family

Marlyn Minkin is a counselor/therapist with extensive experience both working with individuals who are deafblind and working with families who have a family member who is deafblind. The following condensation/excerpt is based on a presentation which Ms. Minkin gave at the Conference on Deafblindness in Vancouver, British Columbia in May 1996.

The experience of having and raising a deafblind child transcends culture. The threads of similarities are more common than the differences. The medical and educational opportunities may differ from country to country, from state to state or from school district to school district. However, the personal impact on individuals and families relates as much to family and individual coping skills as it does to external opportunities.

There is no doubt that providing early and continuous medical, educational and personal support to children and families alleviates much of the unnecessary stress to what is already a difficult and challenging situation. Professionals who are knowledgeable and comfortable with deafblind children and their unique and special needs are critical to the well-being and adjustment for families with deafblind children. More importantly, professionals who listen and join with parents in creating a problem-solving team are able to provide necessary support and allow parents to do the job they do best—parenting!

Parents of deafblind children are first and foremost parents. They are as diverse in their backgrounds, beliefs, lifestyles or any other aspect of human nature as any group of people who happen to share a common experience.

For many families who were leading relatively private or anonymous lives, the changes that occurred following the birth or the diagnosis of their deafblind

child is enormous. Often, in urban areas, families report an average of 20 to 30 medical, educational and support people involved in their lives. They often live with professionals in and out of their homes and lives. They must answer personal questions they have never been asked before. Each professional brings well intended advice, suggestions and “answers”, some of which are unsolicited.

All of the issues already present in each of our lives are quickly intensified for parents who have a deafblind child. The stresses brought about by the necessary changes in their lives are intensified and developmental stages of adult life often happen before they would normally occur. In other words, the stress is like living in a greenhouse under grow lights. Relationships that may have taken years to undergo changes are pushed quickly into challenges. All of these factors must be considered by and for parents of deafblind children. Hopefully, parents can be encouraged to be more kind and gentle to themselves by acknowledging this experience.

It is our hope that we all continue to listen to parents, to grow and share together. If we can further develop our understanding of the impact of deafblindness on a whole family, it will be possible to assist future generations of parents in lighting their load. For this goal, we all need to work together—parents, deafblind adults and professionals. Conferences and retreats are an example of making that happen.

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Growing Together: Understanding the Emotional Impact of Disability

California Deaf-Blind Services recently had the opportunity to bring Marlyn Minkin to California to facilitate a series of workshops promoting parent and professional collaboration. Each regional workshop was structured to be sensitive to the needs of both parents and professionals by featuring two strands, one day for professionals who work with children who are deaf-blind, and one day for family members of a child who is deaf-blind.

Each of the professional strands allowed participants to share their backgrounds and experiences working with children who are deaf-blind, as well as their questions regarding the needs of families. A unique feature of each professional day involved the opportunity to witness a family session/discussion which Marlyn facilitated with a group of parents who have children who are deaf-blind. This “fishbowl” offered insight regarding the hopes, dreams, and fears of families, and served to underscore that working effectively with families and establishing partnerships begins with understanding the perspective and experiences of families. Comments from participants at each of the three regional professional strands included the following:

“Gets down to the crux of what is of primary importance, understanding ourselves so we can understand others better, understand what we share as human beings, respect how we are different.”

“A workshop/experience that helped me realize the impact of my own unexplored emotions on my value system and perceptions of the families I work with. Emotionally wrenching but worth every minute for the family insights!”

“This workshop gave me a much better understanding that the emotional impact of disability can be very long if not lifelong process.”

“I’m glad to get a look at how I, as a professional, can put a more human understanding of the families I work with ahead of my drive to offer solutions that I think will make a better life for their child.”

“I would hope that the honesty and courage I saw in the parents of disabled children can become part of my work with students and families.”

“This workshop helped me as a professional ‘get out of the box’. Getting out of the box requires empathy and understanding.”

“The workshop today made me realize that it is the relationships I have had with students who are deafblind, the relationships I have had with families, and the relationships I have had with other professionals that have meant the most to me personally and challenged me to do my best professionally.”

“I feel that anytime parents and professionals get together wonderful things can happen.”

Each of the family strands brought together families from diverse cultural backgrounds and with different life experiences, but who share the experience of raising children who are deaf-blind. For some participants, this was the first time they had met another parent who had a child who is deafblind. Families had the opportunity to share experiences on a parent-to-parent basis, to express their feelings and support one another. Comments from participants at each of the three regional parent days included the following:

“Ms. Minkin provided a rare opportunity for people to explore their feelings. So much of what we do is mechanics; with all the professionals in our life there’s rarely room for feelings.”

“My experience in today’s workshop helped me realize that we have some very brave and outspoken parents to take the time out and courage to talk about one of life’s most precious gifts, their children...”

“I’ve never had the opportunity to fully express my fears and concerns in an atmosphere where others could fully empathize and support me without judgment or explanation.”

“I learned a lot not only about other families (and connected with), but about myself and my husband.”

“I enjoyed the workshop because the sharing and experiences allowed me to better know my feelings and thoughts and allowed me to enter a sense of community with other parents.”

“Rare and unique opportunity for parents of children who are deafblind to meet together. Thank you so much.”

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California Deaf-Blind Services thanks workshop participants for their reflections, the parents who joined the “fishbowl” / discussion sessions on the professional days for sharing so openly, and Marlyn Minkin for facilitating these forums. It is through understanding and supportive partnerships that families and educators can share hopes and dreams, and work together to plan for and meet the needs of children who are deaf-blind.



**Don't forget to check the
CDBS website regularly
to keep informed of
upcoming events!**



**Point your browser to:
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Mental Health Concerns for Families: Results of a Focus Group Study on Deafblindness

*by Cathy Kirscher
Helen Keller National Center*

When do families with a deafblind child need additional emotional support? When they need support, how do they get it? What suggestions could they pass on to other families who might be going through similar experiences? All of these were questions asked to family members during a focus group study, part of an affiliate grant established in 1996 from the Helen Keller National Center (HKNC) to the California School of Professional Psychology (CSPP) to do research and training on mental health issues related to deafblindness.

Five major areas of concern emerged during these focus groups with family members as times they needed additional emotional support. These areas included issues surrounding communication with their deafblind family member, medical diagnosis and crises, educational decisions, vocational barriers, and social and emotional adjustments.

Some of the social and emotional adjustment issues brought up by family members included:

- Guilt – “Did I cause the deafblindness? Could I have done something differently?”
- Grief issues – mine and my child’s.
- Loneliness for my child – lack of peers. “My child has never been invited to a birthday party.”
- Developmental delays – progress is different from other kids the same age.
- Competence as a parent of a child with special needs. “I felt bad asking for respite care. I should be able to do it all.”
- Anxiety for the future – “Nobody cares for our child as well as our family.”

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Mental Health Concerns for Families (continued from page 3)

Family members were then given the opportunity to share some suggestions with others who might be going through similar experiences related to the social and emotional adjustment that comes with having someone in their family who is deafblind.

Suggestions included:

- “Understanding the genetics of my child’s disorder helped me through the guilt that I had somehow caused this to happen.”
- Push independence for your child; it’s sometimes easier to do things for them, but they won’t grow as much as they can.
- Look for creative outlets to combat your child’s loneliness; “connections” for a child who is deafblind don’t just appear.
- Teach parents how to develop support for their own mental health needs – keep a balance in your life of fun, family, and self.
- Talk with other families with kids who are going through similar issues, and include the brothers’ and sisters’ concerns.
- Become organized as not to be overwhelmed.
- Look into assertiveness training.
- Ask for respite care; recognize that you need to get away once in awhile to feel renewed. “If you don’t take care of yourself, you can’t take care of your child.”
- Have counseling available for all family members, including someone to reach out and talk with by phone.
- Look at a Futures Planning model to develop goals with—and for—your child.
- Understand that grief is cyclical – “My own grief welled up recently watching my two-year-old grandson learn something so quickly. Sometimes we wait months and years for some little increment of progress with my [deafblind] daughter.”
- Meet successful deafblind adults as positive role models for you and your child.

This article has touched on but a few of the concerns and suggestions initiated by family members whose lives have been touched by deafblindness in a loved one. Their generosity in opening up about the mental health concerns, and ability to share their insights, may help others who might follow a different path to helping their family be stronger and healthier.

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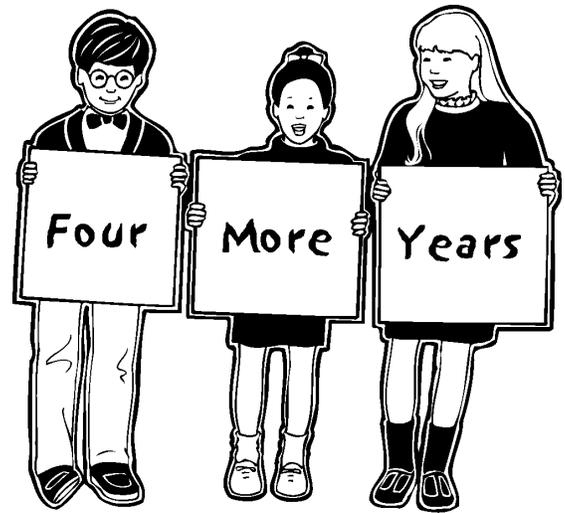
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CDBS Refunded

by Maurice Belote



We are pleased to announce that California Deaf-Blind Services has been refunded for another four-year cycle by the U.S. Department of Education Office of Special Education Programs (OSEP). CDBS will be directed by Dr. Lori Goetz of San Francisco State University. In addition to the main project, we also received funding for an optional project for which we submitted an application. This optional project is called a matchmaker project because we were required to demonstrate that we had generated matching funds for funding requested from OSEP.

For the benefit of all our clients who have been receiving CDBS services over the years and for those who are new to our services, the following is a brief description of the new projects. The new activities address the fact that there are over 1,300 infants, toddlers, children and youth in California who are deaf-blind, and CDBS staff—which is small in number—cannot adequately serve all clients in California without building local capacity for service provision.



Key Features of CDBS for 1999–2003

Communication Trainings. Of all the project activities in which CDBS staff is involved, the one that we do most frequently is to help develop formal communication systems for individuals who are deaf-blind. Communication systems is the most frequently addressed topic in both trainings and technical assistance activities. Because of staff turnover at the local school and agency level, we sometimes find ourselves training over and over in the same area on the same topic. The first major goal of the new project will be to develop local capacity by empowering local regions to assist with the development of communication systems for their local clients. CDBS will develop twelve training

teams throughout California that can conduct twice-a-year trainings in their local areas. Each team will have four people, and teachers, parents, specialists, and administrators will all be invited to participate. The twelve teams will correspond with the twelve regions of the state's Comprehensive System of Personnel Development (CSPD).

Themed Trainings & Technical Assistance. Twice each school year beginning in the spring of 2000, CDBS will conduct comprehensive trainings on topics that are identified as the highest priorities by those of you we serve. These trainings will include both satellite trainings and regional institutes. Attendees will be asked to participate as members of a specific student's team. This will facilitate coordination between all members of a child's team—including service providers and family members—right from the start. The trainings will also include information on how to share the information with others, so that team members may be available to others in their local areas to provide assistance and support. Following the series of trainings, technical assistance will be available from the CDBS Educational Specialists and Family Specialists on the training topic, as well as related topics as needed.

Family Network. CDBS will continue to support and expand our network of family members who are available to assist other family members around the state to address specific concerns and problems. Family Network members will receive comprehensive training through local and regional Family Resource Centers on topics such as communication skills and the emotional impact of disability on family dynamics.

Family Camp 1999

by Jo Anne De Jaco

Rustic log cabins, the smell of pine trees, and the crystal blue water of Eagle Lake was the perfect environment to encourage families to relax and enjoy just being a family. The CDBS and Camp Me & My Family 1999 Summer Family Camp 1999 was a tremendous success. As always, committed counselors and teamwork were the key elements to this success.

Camp has always been a collaborative effort between California Deaf-Blind Services (CDBS), Camp Me & My Family (CMMF), and the Coalition of Parents and Educators Deaf-Blind (COPE-DB). In addition, this year we received tremendous support from the Family Resource Center in Susanville. The R.A.I.N.B.O.W. Family Support & Resource Network assisted us in finding local resources for a Spanish language interpreter—at the last minute, no less—and with recruitment of many of our incredible counselors. Many thanks to Kathleen Colvin and the R.A.I.N.B.O.W. Family Support & Resource Network!

This year, we chose a new location for camp—Camp Ronald McDonald at Eagle Lake, located in Susanville, CA. Rustic log cabins rested on the edge of the lake and were surrounded by pine trees. The camp offered many activities including fishing, boating, archery, and many open spaces for bike riding and hiking. And of course, we had more than our share of mosquitoes!

Several families who attended this year had never been to a family camp and traveled long distances, unsure of what to expect and how they would manage so far away from home. For a few, this was their first experience with their child away from home. Some families, who had participated in previous camps, welcomed what they knew would be quality time spent

with their families and the bonding that takes place when spending time with other families who share many similar experiences. Many parents expressed a great deal of joy seeing their children who are deaf-blind having experiences and participating in activities that are not available to them at home.

Having a brother or sister who is deaf-blind can create some challenges for these siblings. Part of the camp session was dedicated to supporting siblings with the time and place to express feelings and issues they experience. For the younger siblings, art therapist Lisa Kully encouraged her group in learning about and sharing their feelings through art activities. The older siblings that nature with Molly Brewster,



enjoyed all could offer Haggerty—who is a sibling support specialist. Molly led her group on hikes (or they led Molly) and her group had many discussions while enjoying activities such as boating and fishing.

The first night, after families and counselors met and participated in a group art activity, the staff at Camp Ronald McDonald led a night hike. The group was fortunate to have Skylar's dad, Jon, join in the hike. Jon was very helpful in identifying the constellations for those of us who can hardly spot the Big Dipper! The second night, counselors performed skits for the families and everyone sang camp fire songs. For our last night we had a costume carnival and line-dancing extravaganza. There were carnival games, and we all danced the Lodi Reel & Funky Chicken until everyone was completely exhausted.

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Family Camp 1999 (continued from page 7)

Some of the costumes were crafted by hand in the art pavilion. All the campers enjoyed tie dyed T-shirts, paper mache, painting, and a truly endless array of art activities. Campers collected leaves, twigs, snake skins, and numerous other items throughout their stay to paste into their experience books.

While the children were having fun enjoying camp, parents were able to meet and share experiences with each other. Marlyn Minkin facilitated parent groups each day of the camp session. For many parents, this time together was their first opportunity to share feelings and experiences of raising a child who is deaf-blind. Families discovered they are not alone in their unique, and often challenging, daily lives. They found that other families also struggle with not getting enough sleep, worries about the program their child attends, medical issues, the challenges in communicating with their child, and raising children who do not have disabilities, but who also have many needs. Marlyn also provided one to one counseling sessions for parents throughout camp.

Behavior specialist Kim Smalley led a workshop titled "Behavior as Communication". For many children who are deaf-blind, their thoughts, wants, needs, and feelings are expressed through behaviors, some acceptable, some not so acceptable. Some can be a real challenge. Understanding the c o m m u n i c a t i v e function of behavior, and responding to it appropriately, whether by meeting a need/desire or through redirection, is what Kim and the families addressed. Many families had individual time with Kim to discuss issues specific to their child.

Equally as important as being able to meet other families and sharing experiences, is taking time to pamper yourself. Nancy Robinson, certified massage therapist, provided massages for the parents throughout the camp session. It was evident by the euphoric, relaxed looks on the faces of parents after returning from a massage that their stress and worries had been massaged away, even if it was just for a little while.

Parents were also given an afternoon to just "get away". They were all given a picnic lunch, full of wonderful treats, and carte blanche to have an afternoon to themselves. Some parents chose to spend time as a couple or to hook up with other parents and escape. For some, catching up on long overdue sleep fit the bill perfectly!



All the coordination and planning that goes into camp is not enough to make camp happen. Families would not be able to participate without having fully qualified counselors to

work with their children. A full day of training was required before counselors began to work with campers. We needed people with experience working with children, with and without disabilities. This year, many counselors were professionals that work in special education and some were students working towards their special education degree. We also had the support of the enthusiastic staff of Camp Ronald McDonald, who led fishing, boating, hiking, swimming, and archery activities.



Interest in strengthening the Coalition of Parents & Educators Deaf-Blind (COPE-DB) was also renewed. Several families expressed an interest in organizing regional events, such as a picnic. If you have any interest please contact Cindi Avanzino at CDBS.

One of our hopes is that the wonderful camp experiences and memories shared by all who have attended camp, this year and in previous years, continues to be available to families every year. Camp Me and My Family is optimistic that future camps will be held in California. As is often the case, fundraising is the primary challenge. If you have any interest in becoming part of the Board of Directors or in helping with organizing in any way, please contact Cindi Avanzino or Jo Anne De Jaco.

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Making Connections: Families Sharing Information and Experiences

by Gloria Rodriguez-Gil

“Making Connections: Families Sharing Information and Experiences” was designed to meet the needs of the Spanish-speaking families who have children that are deaf-blind or visually impaired with multiple disabilities in Southern California.

At the end of the day, it was easier for the families to share their feelings. All felt that there is a need for more activities of this kind. They welcomed the support and opportunity to network. They were able to start building relationships with other families who share language, culture and feelings about their children with special needs.

Families suggested topics they would like to see covered in the future: communication strategies, the effect on the family of having a member with disabilities, the extent and availability of specific services for families, and behavioral management were determined to be their highest priorities.

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The workshop, offered through California Deaf-Blind Services (CDBS) was coordinated by Gloria Rodriguez-Gil and Jo Anne De Jaco. It was offered at the Blind Children’s Learning Center on August 28, 1999 and was a great success. Sandra Renteria, a parent-professional from Los Angeles Unified School District Parent Resource Network did a presentation on the IEP process. Myrna Medina, Juan Medina and Teresa Becerra spoke about their children who are deaf-blind and how they have accessed the educational system in order to meet their children’s needs.

We were pleased with the attendance. Eighteen people, representing thirteen families, contributed to attain the workshop’s goals: to obtain information about the IEP process, to build advocacy skills among Spanish-speaking families, and to network with other Spanish-speaking families who have a child with deaf-blindness or visual impairments and additional disabilities.



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