

## Juanito's Achievements: Improvement Through Team Work

(translated from Spanish)

by Rosa Salas

**M**y name is Rosa Salas. I have an 8 year-old son named Juan Carlos who is deaf-blind. We call him Juanito at home. As the mother of Juanito, I am very proud of him because he has shown us that despite his multiple disabilities, he has been able to overcome many obstacles and achieve incredible things.

Juanito communicates through gestures, vocalization, objects and sign language. We communicate with him through tactile cues, object cues and tactile signing which we pair with spoken words. He uses hearing aids and these help him hear different sounds and words that sometimes he is able to repeat. He can also hear music with his hearing aids, and this is one of his favorite activities. Now he shows interest when two or three choices are given to him and he has the opportunity to choose one.

It did not take long for Juanito to start walking. Soon after, he was off his bottle and started to drink from a cup. He is also walking with his cane that helps him move around on his own, he wears his backpack to and from school, turns on the stereo and does a lot of other things. My main focus now is to potty train him. All of these achievements have been possible because all the team work from his school, California Deaf-Blind Services and Project SALUTE (California State University, Northridge).

Juanito will be attending a new school next year and I am concerned that this school might not have the services to meet his needs. I think this is the concern of many parents. My recommendation for the school district is to look at every case individually, to find the

resources our children need, and to give our children the opportunity to show what they are capable of doing. What we would like Juanito and other children like him to do is to learn to be independent in life. I recommend that all families start looking for school programs a year in advance and to have everyone work together as a team—this helps ensure positive results.

One year ago I started going to school to learn English, and now I want to learn sign language. I invite all parents to learn things that will help their children, and to stay informed. We are the voice of our children, and we provide the encouragement they need to progress. I will end with one more piece of advice: do not look back, but always look forward.

### **SAVE THE DATE!**

California Deaf-Blind Services and Project NEEDS  
present the  
**2002 California Conference on Deaf-Blindness**

Thursday to Saturday, May 16-18, 2002  
San Diego, California

Keynote Speaker: Prof. Dr. Jan van Dijk

The conference will include three age-specific workshop strands: Early intervention, school age education, and transition from school to adult life. Workshops and large group sessions will be led by state and national leaders in the field of deaf-blindness.

# What's in a name?

or

## A Parent's Coming to Terms with the Diagnosis of Deaf-Blindness

by Jackie Kenley, CDBS Family Specialist

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**O**ur daughter, Laura, just celebrated her 16<sup>th</sup> birthday. Laura is a happy, petite young lady with a big smile, a great giggle, and she is a family member who keeps her family jumping! She walks around her world well although cautiously and finds her way easily in a familiar environment. Laura now rides and steers a three-wheel bike and is water safe in a pool. Her family, staff, schoolmates and friends communicate with her through sign language and gestures close to her field of vision and she signs to us her wants and occasionally her feelings. This young lady can see a piece of chocolate (her favorite) from several feet away. In our family there is lots of noise. This does not disturb Laura, however, for she does not show signs of hearing although she has enjoyed vibration from loud speakers and music. She loves the water—be it a bath or a swimming pool.

As I think back 16 years ago, I can remember the overwhelming feelings my husband and I felt as we were given an early diagnosis for our third child, our beautiful little daughter. She had been born at a good weight with an uncomplicated pregnancy and birth. Two days after her birth all these names were being attached to her: blind, deaf, heart defects, mental retardation. We could not cope with this information and Laura was becoming a diagnosis rather than the beautiful baby that we saw.

Through months of seeking out the opinions of professionals and then years of early intervention programs, we began to find Laura's strengths and began to make our way through the maze of therapies and special education. We were also beginning to realize—with help from knowledgeable professionals—what Laura's needs were to help her communicate and understand her world. The professionals who were closest to the mark about her learning needs were involved with individuals who are deaf-blind. What a tough term that was for me as a parent. Both of those terms rang of something so overwhelming!

Most individuals considered to have deaf-blindness possess some residual vision and/or hearing. Some

persons who are deaf-blind have usable vision and/or hearing and some have none. There are amazing ranges of vision and hearing in this community of people. I have worked with folks at camp with no usable vision or hearing who amaze me with their skills. Is it perhaps obvious by now that I am not only a parent of a child who is deaf-blind but I also decided to work for California Deaf-Blind Services?

Being deaf-blind means that the combined losses in vision and hearing affect a person's world in a special way and that that person will need certain skills to communicate with others and make sense of their world. Often people who are trained in deaf-blindness will find students in classroom settings who are affected by this multi-sensory impairment but who are not being helped with the specific skills they need for communication and interpretation.

California Deaf-Blind Services is now in the process of establishing a statewide network of local Family Support Providers who will work together with their local Family Resource Centers. CDBS staff felt that it made more sense to facilitate linkages between family members of children who are deaf-blind and their local FRCs than to reinvent the wheel by creating a parallel system of family-to-family support. The Family Support Providers will be families of persons who are deaf-blind and will receive training from CDBS and their local Family Resource Centers for working with other parents. If you (or someone you know) might be interested in this Family Support Network, please have them contact CDBS.

As I parent, I can attest that coming to terms with the term "deaf-blind" and getting in touch with California Deaf-Blind Services has been an important and ongoing help for our family. Please contact us if you know of someone who could benefit from CDBS.

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*This article also appears in the current issue of the Support for Families newsletter. Support for Families is the family resource center serving San Francisco.*

# A New Model for Family Support: The CDBS Network of Family Support Providers

by Maurice Belote, CDBS Project Coordinator

California Deaf-Blind Services (CDBS) is working to ensure that family members of children who are deaf-blind have access to other family members for the purpose of peer support and guidance. CDBS staff understands, however, that there is no need to create a duplicate or parallel family network—many Family Resource Centers (FRCs) around the state already operate successful, effective family-to-family support networks. The goal of CDBS is to make sure that interested family members from around the state are linked with their local FRCs, that the FRCs benefit from the training that CDBS conducts, and that Family Support Providers are supported by CDBS in whatever way they need in order to be effective support providers.

CDBS has currently identified 17 family members throughout the state who are willing to serve as Family Support Providers (FSPs). These FSPs will, through coordination with their local Family Resource Centers, provide family-to-family support to other families in their local areas. FSPs are free to make any level of time commitment they would like, from a few minutes a week to a few hours a month. The level of involvement is as flexible as each individual FRC allows.

CDBS staff is available to FRC personnel—paid and volunteer—to provide training specific to deaf-blindness. In addition, CDBS can provide FRCs with print and video materials on issues related to deaf-blindness, including CDBS Fact Sheets and video tapes of past CDBS-sponsored interactive satellite broadcast trainings.

Every summer during the current funding cycle, and as the CDBS budget permits, we will bring all the Family Support Providers from around the state together for the purpose of learning, sharing, and networking. This will be an opportunity to meet other FSPs, share stories and challenges, learn from one another, and make connections that may last a lifetime.

The following family members have joined the Network and have started the process of making formal links with their local Family Resource Centers. CDBS wants

to acknowledge and thank these individuals for agreeing to be a part of this project, and for giving of their time to help other families facing similar issues.

## A huge CDBS THANK YOU to our Family Support Providers:

Theresa Becerra, North Hills  
(Los Angeles County)  
Nancy Cornelius, San Diego  
Martha De La Torre, Long Beach  
Casey Fisher, Cobb (Lake County)  
Patricia Frias, Petaluma (Sonoma County)  
Miriam Gomez, Montebello (Los Angeles County)  
Faye Groelz, San Jose  
Michele Hatfield, Bakersfield  
Wendy Keedy, Riverside  
Mary Lapka, Gridley (Butte County)  
Sandy Lockett, Rancho Santa Margarita  
(Orange County)  
Anita Malani, Fremont  
Herlinda Rodriguez, Downey (Los Angeles County)  
Stacey Rogers, Oakland  
Bethany Stark, Pacific Palisades (Los Angeles County)  
Sandra Suitor, Sacramento  
Pearl Veersart, Los Osos (San Luis Obispo County)



## and to the two CDBS Family Specialists:

Myrna Medina, Monterey Park (Los Angeles County)  
Jackie Kenley, San Francisco

For more information about the Network, contact Family Specialists Jackie Kenley or Myrna Medina at 800-822-7884 (voice/TTY).

Family Resource Centers are located throughout California; it doesn't matter where you live, you are within the boundaries of an FRC. Some FRCs focus on early intervention, while others serve families of children of all ages. For more information on FRCs, visit:

<http://www.virtualstockton.com/families/frcn.html>

# What's happening with COPE D-B?

Coalition of Parents and Educators Deaf-Blind

COPE D-B conducted two regional picnic-type events this year. The first picnic was held in August at Garvey Park in Monterey Park (Los Angeles County) and the second in September at Rio Bravo Resort outside Bakersfield.

These two COPE D-B events were a great success! The photos speak more than many words. The success and input from the families involved have encouraged us to continue the events where they have already been established in the Los Angeles and Bakersfield/Kern County areas, and to begin yet another annual regional event in northern California.

## Garvey Ranch Park



Larry Rhodes leads kids in a game at Garvey Ranch Park.



Aren't brothers great at picnics?

We learn as we go and we hope COPE D-B will continue to grow. We now have a strong core of over 20 families and we hope that more people will step up to leadership roles in the organization.

Contact Myrna Medina or Jackie Kenley at 800-822-7884 (V/TTY) if you are interested in finding out more about COPE D-B.

*COPE D-B is funded in part by a grant from the Hilton/Perkins Program, and has reapplied for continued funding of this organization.*



## Rio Bravo Resort

Friendship and support was pervasive through the day as COPE D-B in collaboration with California Deaf-Blind Services held a picnic on September 15, 2001. In memory of those who lost their lives days before and in honor of those helping in relief efforts, a poignant moment of silence was held.

The picnic, which drew families, educators and Deaf-Blind Services Staff from Northern and Southern California, was held by the swimming pool at the Rio Bravo Resort in Bakersfield. The ideal setting lent itself to casual conversations under the shady trees, great swimming in the refreshing and lovely pool, and many appreciated

opportunities for relaxation all through the day. The luncheon as well as a gigantic birthday cake for a guest who had traveled from Oregon were delicious. The pool was *the* place to be as temperatures soared well into the 90's.

During the day, important and special bonds were formed among the participants.

Openings were created for future sharing of information about positive interventions for our children who are deaf-blind. At the

end of the day, it was clear from the laughter and smiles of the children that this gathering had been a heart-felt success!

*Wendy Keedy, Parent  
Riverside, California*



Fun at the Rio Bravo pool

Myrna and Agnes  
visit at the  
Bakersfield picnic.



Families join  
together to  
celebrate  
Kendra's dad's  
birthday.



# Fact Sheets

Available in the Following Languages  
Call 1-800-822-7884 to order.

<i>Number</i>	<i>English</i>	<i>Spanish</i>	<i>Chinese</i>	<i>Laotian</i>	<i>Vietnamese</i>
001	Communication	✓		✓	✓
002	Light Sensitivity	✓			
003	Touch Cues	✓		✓	✓
004	Object Communication	✓	✓	✓	✓
005	Tadoma				
006	Ideas for Recreation and Leisure				
007	Awareness of Medical Issues in Relation to Changes in Behavior	✓	✓		✓
008	How to Interact with Individuals with Dual Sensory Impairments	✓	✓	✓	✓
009	Teaching Body Language				
010	Developing Independence	✓	✓		✓
011	Appropriate Touch				
012	Tolerating Touch	✓			
013	Encouraging Exploration	✓	✓		✓
014	Making Changes in Routine	✓	✓		✓
015	Relaxation Strategies				
016	Deaf-Blindness				
017	Innovative Living Options				
018	Alphabet Soup: Acronyms Commonly Used in Special Education	✓			
019	Creating a Need to Communicate	✓	✓		✓
020	Strategies for Successful Medical Appointments for Individuals with Deaf-Blindness		✓	✓	✓
021	Supported Education				
022	Neurological Visual Impairment (CVI)	✓	✓		✓
023	Visual Adaptations	✓	✓		✓
024	Otitis Media	✓	✓		✓
025	How to Create a Communication Dictionary	✓			
026	Considerations When Assessing Children & Youth of Spanish Speaking Families	✓			
027	How to Create a Winning Video Resume	✓			
028	Maintaining a Home-School Relationship	✓			

# Fact Sheet

## Maintaining a Home-School Relationship

*by Myrna Medina, CDBS Family Specialist*

**F**amilies and professionals may have difficulty maintaining a connection and an effective method for sharing information about what is happening at home and school. It is important to understand that maintaining that connection and building relationships is sometimes hard, but always necessary.

The following are some general strategies families can use to establish and maintain a good relationship between home and school:

1. It is very important that, at the beginning of the school year, both teachers and family members understand how information will be shared between home and school, and to understand how concerns and problems will be handled. It is also important for families and professionals to know what to expect from one another.
2. Get to know your child's program; plan to visit your child's classroom frequently, i.e., at least 2 or 3 times a month.
3. Have regular informal meetings with professionals, e.g., teachers, itinerant specialists, 1:1 aides and other staff. To help you remember everything you want to discuss, write down all your questions and concerns you want to share with them.
4. Remember not to be afraid to openly ask questions and to expect answers.
5. Ask the teachers for your child's daily schedule and for information on how this is implemented to accomplish established goals and objectives.
6. Create a daily journal for sharing written comments and concerns on a daily basis from home to school and school to home. A binder with your child's name is a simple tool to use for this communication.

*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.*

7. Create a parents' board in your child's classroom to post important information.
8. Be available to participate in and volunteer for school activities.
9. Whenever possible, make yourself available by phone for any last minute things.
10. Check your child's backpack for important information.
11. Network with other family members to communicate and share important information.
12. Understand that it is important to make the commitment to follow through on any methods that are decided on to maintain the connection and a good relationship between home and school.



# Hoja de Datos

## Manteniendo Una Relación Entre La Casa y La Escuela

*por Myrna Medina, CDBS Especialista Familiar*

**F**amilias y profesionales pueden tener dificultad manteniendo una conexión y un método efectivo para compartir información acerca de lo que pasa tanto en la casa como en la escuela. Es importante entender que el mantener esa conexión y construir relaciones es algunas veces difícil, pero es siempre necesario.

Las siguientes son algunas estrategias generales que las familias pueden usar para ayudar a establecer y mantener una buena relación entre la casa y la escuela:

1. Es muy importante que al principio del año escolar ambos, tanto los maestros como los familiares entiendan como se compartirá la información entre la casa y la escuela, y que entiendan como se resolverán tanto las preocupaciones como los problemas. También es importante que las familias y maestros conozcan que deben esperar uno de otro.
2. Conozca el programa de su hijo(a) y haga planes para visitar su salón de clase con frecuencia, por ejemplo 2 o 3 veces al mes.
3. Tenga juntas informales con los profesionales (por ejemplo: maestros, especialistas, asistentes 1:1 y algún otro personal). Para ayudarse a recordar todo lo que usted desea discutir, escriba las preguntas y preocupaciones que le gustaría compartir con ellos.
4. Recuerde de no tener miedo de hacer preguntas abiertamente, y de esperar respuestas.
5. Solicite al maestro el horario diario de su hijo(a) y pida que le explique como se implementa para alcanzar las metas y objetivos ya establecidos.
6. Confeccione un diario para compartir diariamente por escrito todos los comentarios y preocupaciones de la casa a la escuela y de la escuela a la casa. Una carpeta con el nombre de su hijo(a) es una herramienta muy simple que se puede usar como una manera de comunicación.

*Las hojas de datos de Servicios Para Sordos-Ciegos de California son para ser usadas por ambas 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.*

7. Solicite un pizarrón para los padres en el salón de su hijo(a) para colocar cualquier información importante.
8. Esté disponible para participar y ser voluntario en actividades escolares.
9. Cuando sea posible, esté disponible por teléfono para cualquier imprevisto.
10. Revise la mochila de su hijo(a) por si hay en ella alguna información importante.
11. Conéctese con otras familias para comunicar y compartir información importante.
12. Entienda que es muy importante comprometerse a seguir cualquier método que se decida usar para mantener una conexión y buena relación entre la casa y la escuela.



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