

## 'Knowing the Child' – Personal Passports

by David Brown, CDBS Educational Specialist

The population of children identified as having deaf-blindness is extremely varied, and now covers a very wide spectrum of etiologies and abilities and disabilities. Since the 1980s, because of changes in the nature of the population, deaf-blind specialists have found themselves working with more and more children who are at the very earliest stages of communicative awareness in their development, whatever their chronological age; indeed, in terms of communication a large number of them have only pre-intentional behaviors, doing things in response to what they are thinking or feeling but with no intention of trying to convey these things to another person. And their families may have good instinctive knowledge of the children but very little conscious awareness or understanding of what these children are thinking or feeling or wanting. The children's parents are often de-skilled and depressed and frustrated by the impact of the disabilities on the child e.g. very low affect, aversive responses, inconsistent responses, idiosyncratic responses, periods of ill health and regression, self-abusive behaviors, disturbed sleep patterns. Parents

also find themselves further de-skilled by the support services they receive—personnel from these services might be too directive and discourage personal growth or genuine collaboration, they might rely on inappropriate assessment approaches and so undervalue or even deny the parents' insights into their own child, the professionals themselves might feel inadequate to help and then convey this anxiety and sense of hopelessness to the parents, and they might further reinforce feelings of inadequacy in the parents by asking them for information about the child that the parents cannot possibly provide. Empowering parents in this challenging situation, 'humanizing' the child in other people's minds, and including everyone as a positive player in the child's developmental program can seem like an overwhelmingly tough prospect, but one helpful low-tech idea might be to develop a Personal Passport.

### Not enough information, or too much?

All too often children with deaf-blindness, and all the new people coming into their lives, are left to cope with all kinds of transitions with minimal preparation and very little accessible or useful support. At best there may be a few rushed words of explanation, or possibly a longer but nevertheless transient conversation. Maybe the child arrives accompanied by a folder of written information that includes medical reports, IEP documents, old evaluation reports, recommendations for further investigation, and correspondence regarding meetings and various other events. These stacks of undigested material offer little help to anyone searching for a quick and accessible guide to how the child operates, what they like, and how they communicate, nor relevant ideas about what to do if something appears to be wrong.

Even though the child may have had skilled and appropriate assessments of their medical, therapy,

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educational and communication needs, if the assessment recommendations are not picked out and organized in a clear and accessible way, and also translated into practical current advice on how to behave with the child, then they will be of little or no help to unfamiliar people who need to interact with the child in new settings. Even if they can be retrieved from the mass of written material, phrases like 'Tactile objects are Jenny's preferred mode of receptive communication', or 'Maria will need physical support to facilitate expressive signing', or 'It is important to alternate stimulating activities with those that calm throughout Tony's school day' are not helpful without further explanation that truly individualizes them for that specific child.

### **Some useful ideas**

There is a growing range of material aimed at tackling this challenge of turning assessment findings into practical and accessible guidelines that can be genuinely useful to newcomers in each child's life. 'Home Talk: A Family Assessment of Children who are Deafblind' (Harris, Hartshorne et al, 2003), is one of the most recent and most clearly organized. Also popular is 'Could you please tell my new teacher? A Parent/Teacher Guide to Successful Transitions' (Demchak & Elquist, 2001), which gives advice on creating a first transition portfolio for a child. Staff at the New England Center Deafblind Project (DeCaluwe et al) and Sharon Barrey-Grassick at the Senses Foundation Inc. in Western Australia are all doing innovative work on compiling video portfolios and communication guides for children with deaf-blindness. From a different angle, the whole Personal Futures Planning movement has had its own powerful impact upon how children with disabilities are viewed and how they are represented by others (see for example [www.allenshea.com/resource.html](http://www.allenshea.com/resource.html)).

### **Personal Passports**

Sometimes though, time is limited, urgency is high, and there is limited access to resources like video filming and editing equipment, multi-disciplinary teams, time and venues for team meetings, and people with Personal Futures Planning skills. Also, a simpler method that only requires a pen and paper, a ring binder and a few photographs, plus time for thinking and discussing, may be less daunting and more acceptable at the beginning of the process of 'knowing the child'. The Personal Passport idea came from two places simultaneously in the early 1990s—from the Sense Family Centre in London and from Sally Millar at the CALL (Communication Aids

for Language and Learning) Centre at the University of Edinburgh, who have produced a very useful article on Personal Passports ([http://callcentre.education.ed.ac.uk/Resources/Passports\\_REA/passports\\_rea.html](http://callcentre.education.ed.ac.uk/Resources/Passports_REA/passports_rea.html)). The Scottish Executive defines the idea in this way:

"The personal passport is a highly personalized and practical booklet or document written in a simple and direct way, which reflects the individual's personal style as well as supplying information, which can inform others about ways of ensuring comfortable and safe experiences for the child. The passport aims to create a highly positive view of the child and to stimulate more productive involvement of key people by encouraging awareness and confidence, shared knowledge and increased consistency of care." (Scottish Executive, 1999)

### **Heidi and her book**

One of the pioneers in this field was a six-year-old girl called Heidi. Heidi was very hard to "read"—in addition to her vision and hearing difficulties she had severe orthopedic disabilities, a high level of involuntary movements, a seizure disorder, she appeared to show no responses to any kind of sensory input, and was dependent on others for all her needs. Heidi's family felt that they had no idea about what she was thinking or feeling, or what she was aware of. Heidi's parents were asked to spend some time thinking about her likes and dislikes, and how they could identify these from the things that Heidi was doing. Even if they didn't know these things as hard facts, their guesses would be more likely to be correct than anybody else's guesses. They imagined a situation where they would have to leave Heidi with a safe stranger for a couple of hours with minimal time to explain anything—what would they need to write down about Heidi to give to the stranger so that Heidi and her new companion stood a reasonably good chance of having a happy time together? They also decided to write all this information in the first person and include photographs of Heidi so that the information would seem more immediate and personal (Goold, Borbilas, Clarke, & Kane 1993).

Four months later Heidi's parents had created ten simply but beautifully written pages, including photographs, that provided information on Heidi's likes and dislikes and the behaviors that she used to show these, plus information on some of her regular joint routine activities, all written in the first person. A huge change of awareness and understanding had taken place for Heidi's parents; four

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months after stating that they did not understand Heidi at all they were able to write things like:

*"I like holding hands, or having my hands stroked or clapped together."*

*"I love being massaged, but my feet are very sensitive."*

*"I like to sleep – I'm a snoozy girl!"*

*"When I am happy I will smile, giggle, hum (with my mouth open!), move my arms around more."*

*"When I am unhappy it will be quite obvious."*

They also included a 'Crying Checklist' that offered various possible explanations of things that might upset Heidi, ending with:

*"Being 'fussed' over – if it's not obvious, leave me alone for a few minutes and see if I can sort myself out."*

Heidi's parents reported various outcomes from the process of creating the passport:

- ❖ In order to begin the process they had allocated time specifically to sit and talk to each other for the first time since Heidi's birth six years earlier.
- ❖ They had their first realization that they actually knew Heidi quite well, and were interpreting her behaviors a lot during the day, and responding to her on the basis of these interpretations although they had never consciously realized that this was what they were doing. They reported that the quality of their interactions with Heidi developed rapidly once this initial realization had occurred.
- ❖ They first realized that some of Heidi's behaviors, in certain situations and circumstances, were probably intentionally communicative.
- ❖ They discovered for the first time that Heidi used different behaviors with them than with her younger brother, and that she was less expressive at school than she was at home.

In addition to the impact this process had on Heidi's parents, as a document Heidi's Book proved its power very quickly, raising awareness and encouraging more realistic expectations at her school, and particularly impacting positively at the hospital where Heidi went for regular planned medical treatments. Heidi's pediatrician asked all the involved medical and nursing staff on her hospital ward to read it, and during every hospital admission it was

kept at the foot of her bed along with all the usual charts for recording temperature, medication, bowel movements and so on. During Heidi's first hospital admission with the book, her mother reported that hospital staff asked all sorts of questions about Heidi's interests and likes and feelings for the first time, and she also noticed the staff actually speaking directly to Heidi for the first time she could ever remember. Heidi was reported to be the most settled she had ever been during this hospital admission, and when she got home she regained her normal sleep pattern faster than after previous hospital admissions, and her reflux was less evident also.

### **A powerful outcome of assessment findings**

This idea is a particularly useful outcome of the assessment procedure, because so often assessments of these children produce nothing of any practical help and may even be counter-productive, resulting in lower expectations of the child, and reduced self-esteem and confidence for the family. It helps to begin with seeking answers to the questions "What does the child like?" and "How do you know?" and "What does the child dislike?" and again "How do you know?" In this way we always begin at the beginning with basic issues of liking or not liking, wanting or not wanting. It is good to emphasize the process of creating the Passport rather than just the finished product, because it never should be finished unless the child dies, or becomes so fluent in language use that the Passport isn't needed any more. It is important to keep the document individualized, rather than issuing any kind of pro-forma outline where people just fill in the gaps with each child's name so every Passport is more or less like every other one, except for the name and the photographs. People may also need reminding that this is a Personal Passport not a Portfolio, which would usually be a more inclusive collection of information (e.g. Demchak & Elquist, and Harris, Hartshorne et al). Most of all the process offers a chance for growth by the parents and other family members, and maybe for professional staff too—seeing for themselves how much more they know about the child than they had previously realized, and also developing a different way of looking at and thinking about the child. Usually the child emerges from this process as more able and aware and competent than was previously thought too. This process might also furnish a genuine and specific focus for joint discussion between families and involved professionals, one with a direct practical outcome, and one in which the family have the prime access to the really in-depth information. After other parents saw Heidi's Book they produced their

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own, with a great variety of form and content and purpose in the Passports, sometimes with active contributions from the child and other siblings—some were very brief, some full of humor, some highly decorated, some packed with photos, some only concerned with the earliest levels of communicative awareness, but others describing tactile sign use and symbolic objects and daily calendars. All these Passports gave the reader the feeling that the children were right there in the room talking all about themselves.

### Concerns

There are several common pitfalls that cause people to lose their way as they create a Personal Passport:

1. developing a pro-forma and just leaving gaps for the child's name rather than truly individualizing the document (it should reflect both the child and the family who created it);
2. producing a document which does not have a loose-leaf format so it can never be expanded or updated;
3. being creative and esthetic (which is great), but making such a beautiful work of art that the family cannot bear to change it or to discard pages when they are not relevant any longer;
4. putting more and more into the Passport so that it becomes huge and moves beyond the area of communication entirely and has sections on medications, resuscitation procedures, daily routines, the IEP, the daily/weekly school schedule, a calendar of medical appointments, reports from doctors and other involved professionals, and so on. It is not meant to be a file of lots of information about the child—it is **mainly meant to be a portable tool to help comparative strangers quickly and easily know how to get communication (receptive and expressive) right with the child.**

There are relevant concerns about the use, accessibility, and updating of a Personal Passport, some of which are dealt with in the literature referred to, and in the CALL Centre pack. For example, it may be decided to update a Passport at agreed intervals of time, or update when necessary according to previously agreed criteria. Some families may prefer to update the entire document annually and keep each annual edition as an ongoing record of progress, almost like successive volumes in a lengthy novel. A parent told me that she often looked at the family copy of her son's Personal Passport at home

whenever he was having one of his frequent hospital admissions due to chronic health problems. She found this a great support during these difficult times "...because, you know, wherever he is and whatever he's thinking, he's always here at home with us when we read his Passport!"

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#### **If you would like more information**

about Personal Passports and how to include this information in your technical assistance and/or training activities, please bring it to the attention of your child's/student's CDBS Service Coordinator.

# Transitioning to High School

by *Debbie Lackey, Orientation and Mobility Specialist, Ventura County*

*When a student who is visually impaired transitions to a new school, it is common practice for the orientation and mobility specialist to provide instruction in advance within the new environment. The following describes some events and activities that preceded the transition to high school for a student who is deaf-blind.*

Francisco is fourteen years old. He has been without hearing since early infancy and without sight since preschool. He relies on tactile sign language for both receptive and expressive communication. Concept development and related sign language and Braille vocabulary are consistent areas of focus for him. Orientation and mobility may be considered one of his strengths. Once oriented to his elementary and middle schools, he independently traveled routes between multiple destinations on campus. However, the process of orienting Francisco to new environments involves much more than learning of routes. It is about communication, concepts and people.

The process of orientation to the new setting began as soon as possible after the IEP Team had met in the spring and firmly decided on placement. Appointments were arranged for the purposes of educating the high school staff about deaf-blindness and about Francisco's specific learning style and educational needs. But most important to Francisco was the purpose of developing rapport with the people who will be directly involved with him in the coming year. Emphasis was placed on learning names of staff members at the new school and their associated job titles both in American Sign Language (ASL) and Braille. Repetitive visits with teachers were also intended to increase Francisco's awareness and comfort with this transition.

As an orientation and mobility service provider for various school districts, I had the benefit of knowing the teachers in the Deaf and Hard of Hearing (D/HH) program at the new school. This saved time in some respects because they were familiar with me, with orientation and mobility, and had some experience with deaf-blind students in the past. Still, Francisco would offer them a unique experience, as prior students in the program had been able to express themselves verbally and had become visually impaired later in life.

Francisco's one-to-one paraeducator made visits with us to the high school campus whenever possible. This was extremely beneficial. She provided modeling of effective interactions through the use of tactile sign language. Because she had been such a primary person in carrying out specific educational activities, she was able to share information that was relevant to the teachers. Additionally, having his one-to-one involved in the transition activities allowed more reinforcement for Francisco. She was able to create follow-up discussion about the shared experiences using ASL and/or Braille.

Francisco's mother joined us during one of these visits. This allowed her to see specific classrooms, meet teachers and interpreters, and establish contact with people in the main office.

An educational specialist with California Deaf-Blind Services provided a training/presentation on aspects of deaf-blindness. The target audience was the high school staff with emphasis on teachers and interpreters. Attendance was not as high as we had hoped, but great information sharing occurred and the impact was significant for those who were able to attend. Francisco's family and middle school teachers were invited as well.

Teachers from the middle school and the vocational skills program extended invitations to the high school teachers and interpreters encouraging visits and observations so that specific strategies for instruction could be seen in settings where Francisco was familiar and comfortable.

The IEP team members from the two vision programs gathered for a lunch outing with Francisco on one occasion. Having his current and future vision staff members in the same place created meaningful discussions related to the role each person plays. On a later date, Francisco visited the high school vision staff again at the resource room on a different high school campus. He engaged in some Braille activities and began to establish rapport with the vision teacher.

Orientation to the campus was incorporated into our visits so that he had consistency on a few routes. The route from the office to the D/HH room was meaningful to our visits and would be of certain importance to him in the coming year. Landmarks were explored along the

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way to and from the office to ensure that he developed a good amount of detail and understanding of at least one route. When other locations were visited, it was done with the DHH room as the starting point. He explored the location of the restrooms (both girls and boys) which were labeled in Braille and were near the DHH classroom. He was given opportunities to explore and “trail” along buildings so that he could encounter some of the unique characteristics of the campus.

Even with what seemed like a fair amount of preparation, the start of the school year presented a few obstacles. One of the key teachers was absent the first week, and a wonderful interpreter was assigned to part of his day. Because I knew that this was going to be huge for Francisco, I had scheduled in extra time to be with him during the first week. Mostly, I had intended to use this time to help train the one-to-one paraeducator who would be assigned to him. As it turned out, I was his one-to-one for a good chunk of the time. In thinking about this imperfect situation, I wonder about what might have helped the school administrators recognize and address the importance of having this student’s needs covered fully and consistently starting on the first day of school. And, as we end one month into the school year, it is evident that more time should have been spent on the sharing of information regarding specific skill levels, instructional strategies, and the daily schedule and routines of the previous academic program.

Though there are some kinks to work out still, this transition could likely have been more stressful for all involved. Francisco was perhaps less anxious than he might have been if we had not made efforts to visit people last year. There are sure to be benefits of extra time and repetition for a student like Francisco.

Changes in teachers and programs were made easier to handle because he had established relationships with a variety of people on the campus prior to his move.



## A Classroom Teacher’s P e r s p e c t i v e

*Ron Neldberg is a teacher at Mission High School in San Francisco where he serves students who are preparing to transition from school to adult services. In the interview below, Ron answers questions from Gloria Rodriguez-Gil (CDBS Ed Specialist) about his experiences with Laura Kenley entering his program. Laura (Family Specialist Jackie Kenley’s daughter) is 19 years old and has CHARGE Syndrome.*

*Gloria:* Tell us about your program.

*Ron:* This is a transition program serving special-needs students who are 18 to 22 years of age. The program consists of working on vocational, recreation/leisure, domestic, self-care, transportation, and cognitive skills.

*Gloria:* How did you feel about receiving a student who is deaf-blind into your classroom?

*Ron:* Actually, although I have been teaching for many years in special education programs, this was the first time I have had a student who is deaf-blind in my class. At first, I felt apprehensive. However, as I started talking to people about it, I felt more comfortable. Before the student came, her parents and support staff came around to visit different transition classes. Once the selection was made for my class, her vision specialists from the school district came and spent a day with me giving me a lot of information and support.

*Gloria:* What worked well in this transition process?

*Ron:* The support that I received was good. I received tremendous support from Laura’s parents. Another key element was the support Laura was already receiving. Laura’s one-on-one paraprofessional had been working with her consistently for the last three years. She knew how to deal with Laura, and she gave me valuable information so that I, too, could be effective with Laura. It also helped that the vision specialists, the sign language specialists, and the mobility specialists had all worked with this student for many years. In addition, Laura’s previous teacher had sent over to our classroom all of the materials and equipment that was so vital in Laura’s life.

*Gloria:* What other supports would have been helpful in the transition?

*Ron:* Perhaps the school district could provide more adequate classroom space to accommodate this student in a class that includes nine other students, i.e., a larger classroom setting in an already cramped school.

## Successful Transitions Between Programs

*by Maurice Belote, CDBS Project Coordinator*

For educators, transitions that students make from program to program happen so frequently that we can forget the significance of these events to children and their families. For families, transitions can be a time of uncertainty, fear, and doubt about new programs; this is particularly true of transitions from home-based early intervention programs to center-based preschools and from pre-school to elementary school. The following represents some strategies that might help students, their families and educational teams during transitions between educational programs.

**Choose a specific date for the transition and stick to it.** This may seem like a minor point, but consider the following example. A student is slated to move to a new program on a specific date, but two weeks before the date, a vacancy opens in the new program so the student is unexpectedly moved two weeks early. This sudden and unexpected move might get in the way of all of the planned transition activities on the part of both the school staff and the student's family. In addition, the student might not have the opportunity for the farewells with teachers and classmates. We must remember that without a well-planned transition to a new program—such as the case in which a student's bus simply drops him or her off at a new school one morning—the lack of access to information and the lack of control are sure to create a level of passivity in the student that will hinder his or her success in the future.

**Collect all personal materials—including communication systems—and make sure they move with the student.** Some equipment the student uses may not be able to be moved to a new program; there may be issues of ownership among educational agencies. But materials such as a communication system specifically developed for a student must move with the student if we are to give the student every chance to succeed in her or his new setting. It's surprising how often personal belongings of students get left behind during moves—pictures, books, puzzles, CDs, etc.

**Provide the new program with as much useful documentation as possible.** The new staff is sure to appreciate any documentation that might assist them to better meet the needs of the student who is new to their program. This might include a personal communication dictionary, a Personal Passport (visit the Call Center at <http://callcentre.education.ed.ac.uk> for information), videotape footage of the student in various settings, etc. This information is likely to be much more useful than written reports taken from the child's school records.

**Familiarize the student with the new setting.** If possible, allow the student a few opportunities to visit the new program prior to the transition. Of course, these opportunities are essential when a student needs support

*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.*

and time to orient to the new environment, learn new routes, etc., often under the direction of an Orientation and Mobility Specialist. All students, however, are likely to benefit from these early visits; the visits are sure to take away much of the mystery and fear of the pending move.

**Establish time for the sending and receiving teams to meet.** Whenever possible, it makes sense to provide two opportunities for the two teams to meet. The first meeting should occur prior to the move so that the sending program can provide as much information about the student to the receiving team, especially information that might not be in the child's file, e.g., personal communication dictionary, home-to-school log, etc. The second opportunity to meet should occur after the student has been in the new program for a short period of time. This is when the most questions arise—once new program staff has a chance to get to know the student and his or her idiosyncrasies.

**Consistency of DIS staff and/or one-on-one assistant.** Whether a student is moving to a new school or merely changing rooms within a school, it might be beneficial if the student's DIS staff, e.g., vision specialist, physical therapist, orientation and mobility specialist, etc. can follow the child to her or his new program. This will lessen the magnitude of the change; the location and classroom teacher might be new, for example, but at least some of the other familiar staff remains constant and this may make for a much smoother transition. We want to capitalize on the variables we have some control over, such as itinerants and one-on-one aides, since we have much less control over other variables such as buildings and teachers' classroom assignments.

**Set clear and high expectations from the start.** Resist the temptation to wait a few days to get to know new students before clear and high expectations are identified and set. Days turn into weeks and weeks into months, and suddenly the realization hits that time truly is fleeting.

**Change is stressful.** A child may exhibit many reactions to a change as monumental as a transition to a new program, especially if the child had been in the former program for a long time. Some students may be on their best behavior and provide staff with what's been called a honeymoon period, while others might be at their most obstinate and grumpiest worst. Whether a child exhibits some of these reactions or seems to show no reaction at all to the move, we have to remember that the stress of change will manifest itself one way or another—that's for sure.

**Change is good.** Change, as stressful and disruptive as it can be, can also be a positive force in many ways. It is said that when one door closes, another opens, and this open door can be the pathway to new experiences, relationships, and possibilities. The student who has been in a comfortable special day class preschool for three years might discover a world rich with new activities and language models in an inclusive kindergarten. The student who has been in a comfortable high school class might discover the excitement of job training and community recreation found in a transition program.

**Schedule visits to the former program.** Whenever possible, it is a great idea to have the student visit his or her former program. Among students in general education, think about how often they come back to visit former programs and teachers to relish in their own growth and maturation and to re-live the memories and good feelings of days gone by. For students who are deaf-blind, they may not have any idea what happens to former teachers, staff members and classmates when they transition to a new program. It may seem, to the child who is deaf-blind, that these former friends and teachers just vanished off of the end of the earth. In addition, the student who is deaf-blind has probably developed closer relationships with program staff than other students might, and it will help the student deal with feelings of loss if he or she can visit occasionally and keep these special relationships alive.



# Hoja de Datos

## Transiciones Exitosas Entre Programas

*por Maurice Belote, Coordinador de Proyecto de CDBS*

**P**ara nosotros los educadores, las transiciones de programa a programa suceden tan frecuentemente que podemos olvidar la importancia de estos eventos para los niños y sus familias. Para las familias, las transiciones pueden ser un tiempo de incertidumbre, temor, y duda sobre los nuevos programas; esto es particularmente cierto sobre las transiciones entre los programas de estimulación temprana basados en el hogar a programas basados en centros pre-escolares y de pre-escolar a la escuela elemental. A continuación hay algunas estrategias que pueden ayudar a los estudiantes, sus familias y los equipos educativos durante las transiciones entre programas educativos.

**Escoja una fecha específica para la transición y manténgala.** Esto puede que sea un punto menor, pero considere el siguiente ejemplo. Un estudiante tiene programado trasladarse a un programa nuevo en una fecha específica, pero dos semanas antes de la fecha, se abre una vacante en el programa nuevo e inesperadamente el estudiante es trasladado dos semanas antes de lo previsto. Este traslado repentino e inesperado puede que se interponga en todas las actividades de transición planeadas de parte del personal de la escuela y de la familia del estudiante. Y aún más, el estudiante puede que no tenga la oportunidad de despedirse de los maestros y compañeros de clase. Debemos recordar que sin una transición bien planeada al programa nuevo—como en el caso en que el autobús escolar simplemente un día por la mañana lo deja en la escuela nueva—la falta de acceso a la información y de control aseguran crear un nivel de pasividad en el estudiante que le impedirá el éxito en el futuro.

**Recopilar todos los materiales personales—incluyendo sistemas de comunicación—y hacer posible que se trasladen con el estudiante.** Algún equipo que el estudiante usa puede que no se pueda trasladar al nuevo programa; porque pueda que existan interrogantes sobre a cual agencia educativa le pertenece el equipo. Pero los materiales como el sistema de comunicación desarrollado específicamente para el estudiante tiene que trasladarse con él o con ella si le queremos darle la oportunidad para salir exitoso en su nueva clase. Es sorprendente lo frecuente que los objetos personales de estudiante se dejan atrás durante traslados—fotografías, libros, rompecabezas, discos compactos, etc.

**Proporcione al programa nuevo con la mayor documentación útil que sea posible.** El personal nuevo seguramente apreciará cualquier documentación que les pueda asistir mejor en responder a las necesidades del estudiante que es nuevo a su programa. Esto puede incluir un diccionario de comunicación personal, un Pasaporte Personal (visite el “Call Center” en <http://callcentre.education.ed.ac.uk> para información), video del estudiante en varios ambientes, etc. Esta información es probablemente más útil que reportes escritos tomados del expediente de la escuela del niño o niña.

**Familiarice al estudiante con la nueva clase y escuela.** Si es posible, permita al estudiante algunas oportunidades para visitar el programa nuevo antes de la transición. Por supuesto, estas oportunidades son esenciales cuando el estudiante necesita apoyo y tiempo para orientarse en el ambiente nuevo, aprender rutas nuevas, etc., esto pasa frecuentemente bajo la dirección del Especialista en Orientación y Movilidad. Todos los estudiantes, sin embargo, tienen una gran

*Las hojas de información de California Deaf-Blind Services están disponibles para que las usen tanto las familias como los profesionistas que dan servicio a los individuos con impedimentos sensoriales duales. La información corresponde a estudiantes de 0 a 22 años de edad. El propósito de las Hojas de Información es ofrecer información general en un tema específico. Se puede proporcionar más información específica para un estudiante en particular a través del apoyo técnico individualizado disponible en CDBS. La Hoja de Información es un punto de inicio para empezar a reunir más información.*

probabilidad de beneficiarse de estas visitas tempranas; las visitas seguramente quitarán mucho el misterio y el temor del traslado que está por venir.

**Establezca tiempo para que los equipos que dejan y reciben al alumno se reúnan.** En cualquier momento que sea posible, tiene sentido proveer dos oportunidades para que los dos equipos se reúnan. La primera reunión debe ocurrir antes del traslado para que el programa que deja el estudiante pueda proporcionar tanta información como sea posible acerca de él o ella, especialmente información que pueda que no esté en el expediente del niño ej., diccionario personal de comunicación, cuaderno de comunicación entre la casa y la escuela, etc. La segunda oportunidad para reunirse debe ocurrir después de que el estudiante ha estado en el programa nuevo por un período de tiempo corto. Aquí es cuando la mayoría de las preguntas aparecen—una vez que el personal del nuevo programa tiene la oportunidad de conocer al estudiante y sus idiosincrasias.

**La consistencia del personal de servicios relacionados y/o el asistente uno-a-uno.** Sea que el estudiante se esté trasladando de una escuela nueva o simplemente esté cambiando de clases dentro de la misma escuela, puede que sea beneficioso si el personal de los servicios relacionados del estudiante, ej., el especialista en visión, el terapeuta físico, el especialista en orientación y movilidad, etc. pueden seguir al niño al nuevo programa. Esto disminuirá la magnitud del cambio; por ejemplo, la localización y la maestra de clase puede que sean nuevos, pero al menos alguien del equipo anterior que ya está familiarizado permanecen constantes y de esta manera pueda que la transición sea más suave. Nosotros queremos aprovechar todas las variables en las cuales tenemos más control, tal como el personal itinerante y los asistentes uno-a-uno, ya que tenemos menos control sobre otras variables como los edificios y las asignaciones de maestras de clase.

**Establezca expectativas claras y altas desde el principio.** Resista la tentación de esperar unos pocos días para conocer a los estudiantes nuevos antes de que se hayan identificado y establecido expectativas claras y altas. Los días se convierten en semanas y semanas en meses, y de repente se da cuenta que el tiempo realmente está pasando.

**El cambio es estresante.** Un niño puede exhibir muchas reacciones a un cambio tan monumental como la transición a un programa nuevo, especialmente si el niño ha estado en el programa previo por un período largo de tiempo. Algunos estudiantes puede que muestren su mejor conducta y proporcionen al personal con lo que se ha llamado un período de luna de miel, mientras que otros puede que estén en lo peor de su obstinación y mal humor. Sea que el estudiante exhiba algunas de estas reacciones o parezca que del todo no muestre reacción al traslado, debemos recordar que el estrés al cambio se manifestará de una forma u otra—ésto es seguro.

**El cambio es bueno.** El cambio, tan estresante y perturbador como puede ser, puede también ser una fuerza positiva de muchas maneras. Se ha dicho que cuando una puerta se cierra, otra se abre, y esta puerta abierta puede ser el camino a nuevas experiencias, relaciones, y posibilidades. El estudiante quien ha estado muy cómodo en una clase especial de pre-escolar por tres años puede descubrir un mundo rico de actividades nuevas y de modelos de lenguaje en un kindergarten inclusivo. El estudiante quien ha estado muy cómodo en una clase en la escuela secundaria puede encontrar emocionante el entrenamiento en un trabajo y la recreación en la comunidad que se encuentra en un programa de transición.

**Cuando sea posible, haga visitas al programa anterior.** Es una buena idea hacer que el estudiante visite su programa anterior. Entre estudiantes de educación general, piense con qué frecuencia ellos regresan a visitar sus programas y maestros anteriores para disfrutar su propio crecimiento y maduración y para revivir los recuerdos y los buenos sentimientos de tiempos pasados. Para los estudiantes con sordo-ceguera, puede que ellos no tengan ninguna idea de lo que le pasa a las maestras anteriores, al personal y los compañeros cuando ellos cambian a un programa nuevo. Puede que parezca, al estudiante con sordo-ceguera, que los amigos y maestros pasados han desaparecido de la faz de la tierra. Adicionalmente, el estudiante con sordo-ceguera puede que haya desarrollado relaciones más cercanas con el personal que otros estudiantes, y puede que le ayude a él o ella tratar con sentimientos de pérdida si los visitan ocasionalmente y mantienen vivas estas relaciones especiales.

# A Well Planned Move

by Myrna Medina, *CBDS Family Specialist*

**M**any years ago when I left Mexico to come and live in the United States, the move happened so suddenly that I didn't stop to think about what it implied. It was during Christmas vacation and the worst part was that I wasn't aware I would be leaving so soon. I did not even have time to say goodbye to my classmates and friends. I arrived here to a totally different place—a different culture, a different language, and different people. It was very traumatic and scary, and I felt anxious trying to adjust to my new environment.

A couple of years ago I made another change in my life—my family and I moved from Los Angeles to Riverside, which is about 50 miles to the east of L.A. When we were looking for the house it never occurred to me that this would be a big change for my kids, especially for Norman, my 8-year-old who is deaf-blind and has multiple disabilities. Right after we found the house we wanted and knew exactly where we were going to live, I suddenly remembered all that I had been through years ago when I came to the U.S. Deep down in my heart I was concerned about Norman; because of all of his special needs this move was very likely to have a great impact on him.

Keeping in mind the fact that the move would be a challenge, my husband and I started to plan a transition to make things easier for Norman. We knew there were factors working against us like timing and distance (timing because it was during school session, and distance because the new house wasn't around the corner from our old house but instead many miles away). Nevertheless, we were excited about the move.

When designing our transition plan we considered all the factors involved, such as home environment, school for our daughter, school program for Norman, etc. We then asked ourselves, How can we do this? How can we make sure this transition works? And the big question—How can we make sure Norman's new school program is the right one for him?

First, we did not move right away to our new house. We decided to have Norman stay in his old program for the remainder of the school year (since it was almost vacation) in order to minimize the number of changes in his life. We thought this might make him confused with so many things happening at the same time. We chose instead to visit our new home as often as possible. We even spent

some weekends at our new place, exploring and getting familiar with the new home, the neighborhood, and we also visited the new school.

Soon after, I visited the new school program and met the person who would be Norman's new teacher. I explained to her all about Norman's needs and asked how she felt about having a child with deaf-blindness in her class. I inquired all about other related services, and the possibility of meeting with the one-to-one assistant before school started. The next step was to take Norman to the classroom so he could meet his new teacher and she could meet him.

When the school year started, I went with Norman to school for the first few days. Even though we had all met before, everything was kind of new for Norman as well as for his teacher and one-on-one aide. Me being there in the classroom and showing the school staff how to communicate and work with Norman made everything much easier. Norman didn't feel that I had just left him there and the teacher didn't feel so lost. Shortly after that, his educational team and I met to discuss all the information related to Norman.



Thinking about what was best for our children—along with all the planning, time, and effort—made this transition a success. We finally moved into our new home. Norman is progressing in his new program without any major complications. In addition, our daughter likes her new school, too. And they even got a dog named Buster.



# COPE-DB: *Your* Coalition of Parents and Educators Deaf-Blind

by Jackie Kenley, CDBS Family Specialist

**Y**ou might not get asked these questions as often as you'd like, but COPE D-B—your family organization—is asking:

*How can we do a better job?*

*Got any ideas?*

*What are we doing right and what are we doing wrong?*



FJB's Judith Harris greets Michael Tuero and his mother, Yasmina, at the Los Angeles picnic.



## Los Angeles Family Picnic August 28, 2004

THANK YOU to everyone at the Foundation for the Junior Blind for hosting our longest running regional family picnic—five years!

Moms get ready for the big sack race: (left to right) Blanca Horta, Alba Marquez, Jessica Horta.



One of our youngest picnic goers, Jessica Horta enjoys the bright summer sun and her papa Ernesto's arms.

COPE D-B held three family picnics during the summer of 2004—in Santa Rosa, Los Angeles and Bakersfield. Although we feel these events have been successful in bringing families together, we would like to do an even better job in the future.

Our members in the Los Angeles area have requested assistance with a December holiday party, so plans are being made for this event. However, it would be great to have even more parents and educators attend our events. Do you have any ideas how to accomplish this? Would any of you like to plan the events, including choosing places and times?

It is inspiring to see our families becoming a BIG family as we work to support our kids who are deaf-blind, their teams and family members. If you know of a family member, educator, or team member who would like to be included, please phone 1-800-822-7884 and speak to Myrna at extension 25 or Jackie at extension 21.

We are grateful for the support of the Hilton/Perkins Program and the other groups and individuals who sponsor these events!

*Please remember—it takes a family and a village!*

*We are your parent group!*

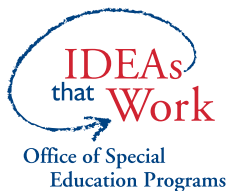
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