



reSources

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Time To Eat (On Overcoming Nearly Impossible Obstacles)

by Wendy Keedy, Volunteer CDBS Family Support Provider

When our daughter Kendra was 2½ years old, following a series of complex medical problems, a well-respected neurologist gently told us that in order for Kendra to have any chance of tasting and trying food by mouth, a medical procedure might offer her an opportunity. You see, Kendra had received a gastrostomy tube at one month of age and had had little success oral feeding safely ever since. Aspirations were common whenever she tried to eat. The doctor felt reasonably certain there was no chance Kendra would be able to eat orally safely. Ever.

The procedure proposed would remove part of her esophagus from her throat and place it on the outside of her neck where it would discharge any food tasted. At that point the food would be wiped away by a caregiver, never having reached her stomach. The benefit would be that the danger of aspiration would very nearly be gone. Nonetheless, imagining Kendra with her esophagus routed to the outside of her body did not sit well.

In fact, the proposal sounded exponentially worse than the problem; the idea was untenable to her father and me. We resolved that despite the sadness of not enjoying food, we could not agree to this surgery. By then Kendra had already experienced approximately 20 different procedures and surgeries under anesthesia to correct a variety of conditions associated with CHARGE Syndrome. From one week of age on, she had had surgeries to repair an H-type Tracheal-esophageal fistula, a tracheostomy, a surgical replacement of the tracheostomy tube site, a repair of a cleft in the soft palate, a stretching of the esophagus, a Nissan fundoplication, tracheal dilations almost too numerous to count, a repair of a double aortic arch and patent ductus arteriosus, and insertions of PE tubes. While she had fared relatively well following the majority of the medical experiences, she had also faced

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life-threatening conditions on at least four separate occasions. To make matters worse, Kendra had facial paralysis and appeared to have slow or sometimes absent peristalsis. Eating orally just did not seem to be in the cards for her. Kendra also is profoundly deaf and has small chorioretinal colobomas.

Although eating and enjoying food is one of life's undeniably great pleasures in that it provides nutrition and a social avenue with which to engage with others, the proposed plan left us realizing that continued eating with a gastrostomy for an unknown period of time in the future was preferable to the concept of further altering her anatomy with unknown consequences and again undergoing anesthesia.

But then, amazingly, some factors came into play that moved us into a new arena of hope. Kendra was able to be weaned from her tracheostomy tube at age 3 and to have it surgically removed at that time. The absence of the tube in her throat opened up a whole new possibility that she would be able to manage the facial paralysis and swallow difficulties she had. In fact, the facial paralysis had lessened shortly after she turned 2 years old. We were thrilled when the swallow study revealed to the Ear Nose & Throat doctor that he could in fact 'clear' Kendra to go forth with feeding therapy.

Kendra's previous eating experiences were limited to her first 6 months and pacifier use during her first few years. She had nursed on and off until the time that aspirations precluded further attempts. And adding insult to injury, Kendra began to bleed in her stomach whenever breastfeeding was attempted. It was not clear what was happening; it appeared she had become completely unable to process breast milk. In fact, she was unable to process anything at that time other than a pre-digested



formula—Pregestimil—which provided the nutrients in the form of amino acids, which are the building blocks of life. The Pregestimil was delivered via feeding tube. Any other substance consumed such as typical baby formula or soy formula resulted in profound diarrhea or internal bleeding.

Due to the aspiration history, the feeding specialist began cautiously with sterile water. Each week or two from the time Kendra turned 3 until she was nearly 4, we returned to the feeding specialist who carefully swabbed Kendra's mouth with a sterile water applicator. The progress was not easy to see, but the therapy kept Kendra in a state where her mouth was being stimulated, and there was no aspiration danger. We waited patiently for the time when the next step could be taken. Sterile water does not generally provide enough impetus to learn a skill as demanding as eating! The swallow study had shown that Kendra's food caught in the area behind her tongue called the valleculae. Whenever food is delayed, the possibility of aspiration increases so the specialist was not eager to move beyond the safety of 'plain old' sterile water. If sterile water was aspirated the ramifications would likely be negligible.

Finally, medical clearance came and Kendra was 'okayed' to proceed with further therapy. The next therapist, a speech language pathologist with advanced neuro-development training credentials, began stimulating Kendra's lips and cheeks with iced water. This thermal stimulation awakened the nerves and improved Kendra's potential to use her mouth for eating. The therapist proceeded to use popsicles that added more incentive to keep trying. Kendra opened her mouth eagerly to taste the minuscule amount of delicious fruitiness.

The therapist noted Kendra's hyoid bone was unusually placed. Each condition added layer upon layer of potential difficulty. The therapist taught Kendra some exercises that delicately moved the hyoid bone. Amazingly, Kendra showed that she was swallowing the Popsicle liquid safely.

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No coughs, no difficulty breathing, and no blueness around her mouth or face appeared.

Greatly encouraged, the feeding expert moved to the next step. To my surprise and delight, she brought a delicious smelling bowl of clam chowder to the table. She was attempting to stimulate Kendra's interest in eating in all possible ways. The aroma must have done the trick because Kendra consumed this pureed substance happily. We watched. Kendra indicated she wanted more. It was working! Kendra was eating soup! There were no problems.

After several visits and a number of different pureed soups, the feeding specialist remarked that if Kendra could eat clam chowder or broccoli soup pureed, she could consume all necessary nutrients by mouth. All we needed to do was puree a balanced diet for her. At this point we all breathed a sigh of significant relief. Kendra was also mastering eating crackers during her therapy sessions. At age five it looked as if Kendra would actually be able to eat enough safely to have her tube removed at some point. We were elated.

Over the next several years, Kendra had illnesses requiring medication to be administered by g-tube and surgeries so we kept the tube as a safety valve. Little by little, it became clear that surgeries were very infrequent now and Kendra could take liquid medication by mouth safely. Plus her general health was improving. She still did not eat any food that was solid or that required chewing, though. It didn't seem wise to remove the tube just yet.

After a visit to another clinic, Kendra started to make progress with chewing. Up until then, any solid type of food other than crackers had only been attempted through a mesh bag that Kendra chewed on to release the flavor of the food. It was not known if Kendra could safely chew the food sufficiently to swallow it without choking. The exercises through the HANDLE Institute stimulated the trigeminal nerve and Kendra started not only eating larger amounts by mouth but she also started chewing foods safely. At ten-and-a-half years of age, Kendra had her stomach tube removed surgically. She hasn't looked back.

Writing this log of Kendra's progress toward eating by mouth has been very emotional. Little did we know when Kendra first aspirated and turned purple as she stopped breathing that there was any hope she might survive, let alone ever eat a typical meal. In fact, the Speech Language Pathologist who was successful in helping Kendra become

an oral eater told us, at the outset, that there was no guarantee Kendra would be able to eat safely as there were few cases to base the projections upon. Children who had the physiologic characteristics that Kendra had had not commonly been able to overcome the difficulties. And Kendra was several years beyond the newborn stage when a baby is 'primed' to learn the intricacies of safe eating.

Kendra is now 19 years old. Some of the things she ate this week include pizza at a friend's birthday party, barbecued chicken, broccoli, an artichoke, coleslaw, fresh sugar snap peas off the vine, fried eggs, Spanish rice, and banana pancakes. She eats almost all things that we eat at our house excluding steak and chops, which are too difficult to chew completely at this stage. When she has a cold, we restrict her diet to foods that are most easy to swallow as sometimes there is swelling that gives her difficulty. For safety, Kendra's IEP calls for only pureed foods when she is at school.

With eating becoming a typical component of Kendra's days, there are other factors associated with food now drawing our attention. While Kendra eats a balanced diet, information is forthcoming in the scientific world related to behaviors that may start or may be aggravated by food that is ingested but not tolerated, or that is insufficiently digested. As Kendra has behaviors that appear to preclude certain types of learning, such as complex language learning, and has significant difficulty with visual processing, we pay attention to the literature and studies on this topic. It is conceivable that certain foods may contribute to difficulties in these areas of development. We therefore keep our minds open and focused on learning more about how digestion affects each of us and what positive steps we can take, such as eating organic food, to increase the likelihood that the food Kendra eats will support her growth and development in the most healthy and beneficial ways.

One thing is certain. The smile on Kendra's face when she shares a favorite meal with friends and family shows us that all the therapy was well worth the time and effort. Early breastfeeding from the day she was born, pacifier use and oral stimulation may have been contributing factors to her ultimate success. Having established a memory for feeding may have been an important element in being able to learn at such a relatively late age. Finding specialists who were comfortable and competent with Kendra's complexities was of primary importance. We say a little prayer of gratitude to them. It has been a remarkable journey.



Living With Late-Onset Seizures

by Jackie Kenley, CDBS Family Specialist

“Life can only be understood backwards;
but it must be lived forwards.”

~ Soren Kierkegaard
(Danish philosopher 1813–1855)



Life is full of new things and surprises—some of which are wonderful and pleasant and some that are just plain scary. I think from the beginning of our daughter Laura’s life, we have faced some of the toughest surprises that parents can face. As Kierkegaard says, we only understand these scary things backwards but I am writing this in hopes of sharing with families while hopefully preparing others.

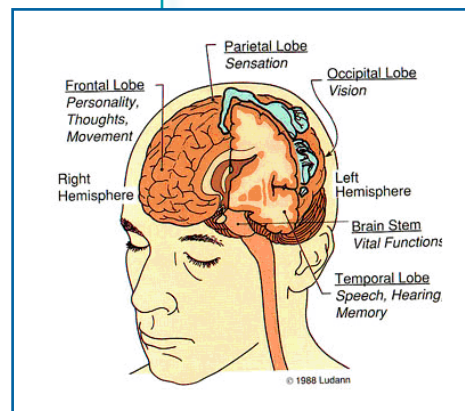
Our daughter, Laura, who turned 21 in February of 2006, has had many things to overcome and learn to live with or around, but she had never had a seizure that we knew of. Laura has CHARGE syndrome and is profoundly deaf and has only limited vision mainly in one eye. She has endured two open heart surgeries for repair of Tetralogy of Fallot and for Mitral Valve Suture. She also had surgeries for ear tubes and for muscle repair in one eye. Her petite body has sustained so much over the years. She is a true fighter and teacher of life for all of us.

In August of 2005, Laura had just finished a long luxurious morning bath. As she was getting out of the bathtub she began to quiver. This was not unusual in itself but the quivering went into shaking and her whole body became stiff. She was unable to hold herself up, her eyes rolled back, and she turned blue around her mouth. I realized that she was not breathing and yelled for my husband to come and help. From that point on we did almost everything wrong! We did not realize what was happening and had no idea what to do or expect. It only felt like Laura was slipping away from us. We called 9-1-1 and Laura’s Dad turned her upside down in case something was caught in her airway that was preventing her from breathing. At one point we hung up on emergency dispatcher!! Somehow the dear people at 9-1-1 called us back and from that point walked us through

a process of obtaining help. We then put Laura on a bathmat on the floor and very soon we had paramedics with us and realized that Laura had begun to breath on her own and was regaining her color.

The rest of that day was spent in the ER having blood tests and CAT scans and speaking with doctors and nurses. The word seizure was used over and over and we began realizing that is what had occurred. I was so relieved when Laura began trying to take the IVs out and signing “eat” and “drink” very energetically. At the end of a long day, we left the ER with some knowledge of seizures and Laura being able to walk and eat and drink. She had not eaten the whole day since she was going to eat right after her bath the morning of the seizure. Laura was sent away with a scheduled EEG and MRI.

Six weeks later, I was called by her teacher at school to hear that another seizure had occurred. She had seemed ill at school before this seizure; she had eaten and been mildly active but not really herself. The afternoon after this second seizure she was quite nauseated and vomited several times. I was told that having a seizure is like “running a marathon” for the body and that we had to allow her time to rest. Thankfully, the next morning she was better.



Laura has had an unsuccessful EEG (she doesn’t like things on her head!) and an MRI under sedation that showed tiny spots of mineralization within the right occipital lobe and decreased size of the right pons (portion of the brain stem) and right cerebral peduncle (stem connecting parts of the brain to each other). The mineralization could reflect prior infection or congenital malformations.

They are suggestive of cortical abnormalities which might increase the risk for seizures. The decreased size of the right pons (in the brainstem) likely represents loss of the axons (parts of nerve cells that allow them to communicate with each other) from earlier cortical atrophy.

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Trying to have the hospital understand Laura's needs during medical testing was a challenge but we finally got the message across. Communication is a major issue in testing and I needed to be the conduit for the medical staff. Since the time of her seizures, Laura has been taking Valproic Acid and her seizures seem somewhat under control.

I am trying to work with the CHARGE Syndrome Foundation and other families to collect documentation on seizure activity in people who have CHARGE syndrome. I also want to include some important information on seizures that may be helpful to some families as they "live life forward".



For more information

Check out this website:



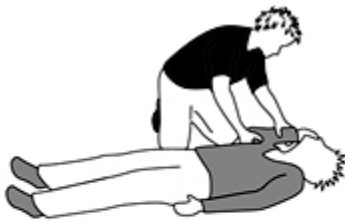
www.epilepsyfoundation.org

This information is from the Epilepsy Action website: www.epilepsy.org.uk/info/firstaid.html



FIRST AID for Generalized Tonic-Clonic (Grand Mal) Seizures

Do...



- + Protect the person from injury (remove harmful objects from nearby)
- + Cushion their head
- + Aid breathing by gently placing them in the recovery position once the seizure has finished
- + Stay with the person until recovery is complete

Don't...



- + Restrain the person
- + Put anything in the person's mouth
- + Try to move the person unless they are in danger
- + Give the person anything to eat or drink until they are fully recovered
- + Attempt to bring them out of the seizure

Call 9-1-1 if...



- + You know it is the person's first seizure
- + The seizure continues for more than five minutes
- + One tonic-clonic seizure follows another without the person regaining consciousness between seizures
- + The person is injured during the seizure
- + You believe the person needs urgent medical attention

Some Considerations and Strategies When Working With Latino Families

by Gloria Rodriguez-Gil, CDBS Educational Specialist

Introduction

Latinos are a diverse population. We come from different countries in Latin America and from different cultures within those countries (see map of Latin America on page 13). In addition to belonging to different countries and cultures, there are also differences that would be found among any group of people—the use of language, level of education and economic attainments, prevalent religious beliefs and ethnic origins, etc. In most of these countries the official language is Spanish but there are other languages spoken (e.g., Portuguese, English, French, indigenous languages). In this article I will focus on Latinos who speak Spanish and explore some of the similarities between their cultures that might help raise your level of awareness and understanding and could help you collaborate with and support these families.

Most of the information shared in this article comes from two avenues: 1) teaming up with Myrna Medina, a Family Specialist for California Deaf-Blind Services who has a child who is deaf-blind, and 2) through our work with Latino families in California. It also includes my experiences working with families of children with special needs in Costa Rica.

Considerations

We have grouped the areas we have found useful in understanding Latino families into six main considerations:

- 1) religion and disability,
- 2) the Latino family,
- 3) concept of disability and independence,
- 4) contact and communication,
- 5) use of interpreters, and
- 6) the view of the professional.

Religion and Disability

The majority of Latin American societies practice Catholicism or other forms of Christianity. In these cultures, religion plays an important part in organizing and interpreting personal and social experience and it is embedded in the activities of daily living.

Some of the families we serve have expressed the reason they have a child with disabilities is because it was the will of God. One mother recalls her process of acceptance of having a child with disabilities:

In the beginning, she felt guilt because she felt she had “done something wrong”. Later on, she went through a stage in which she was “mad at God” because the disability was perceived as a punishment. Finally she came to the conclusion that God probably gave her this challenge because she is a person of worth and God considered her capable of facing this challenge.

Religion is such a strong component of daily life that you find it in popular sayings such as: “Dios aprieta pero no ahorca”; literally “God squeezes but does not choke you”. In other words, God presents you with big challenges, but not of a size and weight that you cannot carry them.

Being part of a religion helps these families with the daily challenge of having a child with disabilities. However, it also carries a risk of passivity because all the decisions could be left to the will of God. Again, a popular Spanish expression illustrates this — “Ayúdate que Dios te ayudará”, which in English is usually expressed as “God helps those who help themselves”.

Still another point of view is embodied in the case of a mother who reported that she, as well as other families of children with disabilities, always carried the hope of a God-given miraculous cure for her child, no matter how old the child was or the severity of the disability.

Religion gives Latino families a sense of belonging to a larger group. Actively participating in a church or other

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types of religious communities offers these families different levels of support within their communities such as social activities, support during difficult times, basic counseling, and food and other basic needs.

The Latino Family, Concept of Disability and Independence

The Latino family is the basic social unit that takes care of its members. Most Latinos will always be part of a family, either a “nuclear” family (mother, father and children) or an “extended” family (several generations of siblings continue the development of their nuclear families while still associated with a progenitor). The extended family is the main structural support for geographical mobility and for the sharing of resources.

In some families—and Latino families are no exception—the condition of a child with special needs may be seen as a “disease” and not as a “disability”, and there is a tendency towards pity and overprotection. This point of view usually changes in the nuclear family as its members become more informed about the disability of their child and as they meet other families of children with special needs. This might not be the case with the extended family because they do not receive the same kind of information as does the nuclear family. Several Latino families have expressed frustration and sadness they feel due to the lack of understanding from their extended family and, as a result, a lack of appropriate support from their extended family members.

When a family member has a disability, there is a tendency to protect this family member by doing things for her or him. When the child has multiple disabilities, the family members’ expectations of independence or partial independence are even less. This last aspect can change as the family receives new information about the child, and as the child learns new skills that demonstrate to the family that the child can do things for himself or herself.

Contact and Communication

The Latino culture gives great importance to oral exchange and personal attention. In addition to receiving written reports, we have found that families benefit from having reports verbally explained to them. Latinos are also less inclined to interact through impersonal communication

modes, preferring instead direct contact through face-to-face conversation.

Some of the families that we serve are more accustomed to interactions within small groups and may seem shy with people outside their social group, such as with service providers of their children with disabilities. This can be magnified by other factors such as limited education, limited command of the English language, and limited familiarity with cultural norms. This shyness can give the wrong impression by suggesting a lack of interest or incompetence on the part of the family.

Use of Interpreters

The use of interpreters is a key component in communicating with Spanish speaking families. The English speaker must remember to pause after each sentence to allow adequate time for translation. Violating this simple rule can cause confusion for the Spanish-speaking family member as well as for the interpreter. The interpreter does not translate word-for-word, but rather translates complete sentences. Sometimes the English speaker uses an expression that when interpreted is still not understood by the Spanish speaker. In these cases, the interpreter first rephrases the English expression. If the meaning is still not clear, the interpreter must stop interpreting long enough to adequately explain the meaning.

When an IEP meeting is for a child who is deaf-blind and also requires an interpreter for Spanish-speaking family members, the meeting will likely require more time than do other IEP meetings. Educational teams for children who are deaf-blind tend to include many people representing several disciplines. When there are more people at a meeting, more time will be needed for interpreting, and therefore more time has to be allotted for the meeting.

View of the Professional

In Latin America, good teachers, therapists or other services providers are viewed as special people. They are considered people with knowledge and experience and also people with a “call” because they have chosen to work with children with special needs.

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The tendency is to place the responsibility for a child's education in the school's staff. When parents immigrate to the United States, they may continue to have this perspective. It may be hard for them to understand that here in the U.S., the point of view is different and that here they are the main leaders of their children's education.

Strategies

Religious Life

- ❖ Be aware that religion is likely a part of the family's belief system and helps them cope with their child's disabilities.
- ❖ Belonging to a religious group or community can be part of the network of support that the family needs.

The Latino Family, their Concept of Disability and Independence

- ❖ Families are more willing to explore different points of view when they:
 - ❖ Learn about the child's disabilities and their child's potential,
 - ❖ Learn how to support their child appropriately at home,
 - ❖ Meet other families of children with disabilities.
- ❖ Whenever possible, invite extended family members to educational and social activities so that they share the same experiences and gain the same information as the nuclear family of the child with disabilities.
- ❖ Visit the family's home so you have a more accurate sense of the family's life and can become more "in tune" with the strengths and needs of the child with disabilities within his family and home environment.

Contact and Communication

- ❖ Families are more likely to share their feelings and thoughts with people who respect them and who are sensitive to the process they are going through. Latinos

pay a lot of attention to the way they are treated. This is part of the "personal contact" culture.

- ❖ Create spaces for informal social interaction and/or encourage Latino families to join agencies and organizations that promote these kinds of activities.
- ❖ When making home visits, allow sufficient time for social interaction before getting down to business. Do the same at the end of the visit—allow time before leaving for additional social interaction.

Use of Interpreters

- ❖ Communicate as much as possible directly to the parents by using an interpreter. Be aware of the appropriate way of using interpreters.
- ❖ Whenever possible, use qualified interpreters. If you are not sure about the skills of a specific interpreter, ask the parents for their opinion.
- ❖ When providing written reports, verbally explain the report's main points to the family.
- ❖ Provide the family with the report written in both English and Spanish—English so they can share the report with other service providers if needed, and Spanish for their own use.
- ❖ Consider conducting an IEP meeting in two sessions if it is expected to be lengthy.

About the "View of the Professional"

- ❖ Help parents understand the key leadership role they have on their children's educational teams.
- ❖ Help parents understand the importance of having goals and high expectations for their children, and the need to clearly communicate these to their children's educational teams.
- ❖ Encourage parents to participate in parent support groups where they can learn more about issues related to their children's disabilities. These are the parents who will be empowered to accept the challenge of becoming leaders and full participants of their children's educational teams.

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www.sfsu.edu/~cadbs

Fact Sheet

Strategies for Successful Medical/Dental Appointments for Individuals who are Deaf-Blind

by Maurice Belote, CDBS Project Coordinator

Many individuals who are deaf-blind have medical needs that may require frequent medical appointments. These individuals also require regular dental care that may also be complicated by physical/health issues. Medical/dental visits can be very frightening for the person receiving treatment if the procedures are not expected or understood. As the individual who is deaf-blind becomes frightened, he/she may express fear through behaviors (e.g., tantrums, aggressive behavior, rigid body postures, etc.) that will make the examination and/or procedure difficult. The visits can also be very frustrating for the families and care providers assisting these individuals during the examinations as they try to explain and manage the behavior expressed.

The following points are some general guidelines to promote a successful and positive experience during medical/dental appointments. It is suggested that family members and care providers review these guidelines with health care professionals when the appointment is made or upon arrival at the office. A copy of this fact sheet can be left with the medical/dental staff to inform them of the needs of their patients who are deaf-blind. [Please note that these ideas represent what might be considered the ideal medical/dental visit and that each strategy may not be possible in every situation.]

1. Try to locate a medical/dental professional who has experience with individuals who are deaf-blind. If you are in need of a referral, call California Deaf-Blind Services (CDBS) at 1-800-822-7884; a CDBS Family Specialist may be able to link you with someone in your area who has information regarding local providers.
2. Call the medical/dental office staff in advance of your visit to let them know what to expect (e.g., difficulty waiting, unusual and/or loud vocalizations, challenging behaviors, etc.).
3. If the family and medical/dental staff can manage this, give the individual who is deaf-blind an opportunity to visit the medical/dental office in advance of the appointment so that he/she can become familiar with the provider, office staff, equipment, smells and sounds, etc. Identify name cues or signs for some of the key people who will be providing the medical/dental services. This pre-appointment visit provides an opportunity to collect sample instruments to use in role-play activities (see next recommendation).
4. Provide opportunities for role-play activities prior to the medical/dental visit. When appropriate, give the individual who is deaf-blind the chance to be the provider and use the sample equipment on others (i.e., family members, teachers, classmates, etc.). Allow opportunities for the individual's peers to do the same with the individual who is deaf-blind. Make the experience fun and relaxed, and use this role-play activity to reinforce language that will be used during the medical/dental visit.
5. Bring something for the person to do during periods of waiting at the office.
6. If the individual has a favorite object and can hold or touch it during the procedure, bring it to the appointment. It may provide the patient with a level of comfort/security that will help him/her through the procedure.

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. Bring the person's medical records to decrease the repetition of developmental history, waiting for records to be sent, and duplication of unnecessary exams. Include addresses and phone numbers of all service providers.
8. Bring information about the person's specific medical issues if the medical/dental professionals are new or unfamiliar with the particular syndrome or condition (e.g., Congenital Rubella Syndrome, CHARGE Syndrome, etc.).
9. Whenever possible, introduce each of the medical/dental professionals to the person who is deaf-blind before the professional touches the person. This can be done with a name sign, a name cue, a concrete object of reference, or a distinctive scent.
10. Let the person know how the exam is proceeding. Tell the person what will happen next and what the reasons are for the particular examinations.
11. Model and reward cooperative behavior, appropriate waiting, confidence, acceptance and relaxed body posture.
12. If medical/dental professionals request it, give them feedback and/or acknowledgement regarding their interactions with the patient and the patient's family member/care provider (e.g., terminology used, bedside manner, emotional tone, willingness to work with you, etc.). This information might be helpful to the professionals when they plan for future appointments.
13. Reward yourself and the patient following medical/dental procedures. Stop on the way home and have a treat, buy some new music or a movie, take a swim at the community pool—whatever you do to reward yourself. As a rule, we don't reward ourselves enough for getting through challenging situations.
14. Collect items to use as a record of the visit so that the experience can be discussed in the future, such as when preparing for additional appointments. The experience can be recorded in an "experience book" that may include photos, objects, words in print and/or Braille or other items that will help the individual remember the event. Be sure to include a record of the post-visit reward so that it might serve as a motivator for future visits.

Tips for Professionals

1. Warm hands or instruments before touching the person who is deaf-blind.
2. Tell the person what each procedure will entail prior to beginning the procedure. This can be accomplished by allowing the person to examine the equipment by touch. You can then touch the patient's body part that will be examined by that piece of equipment. Pause for a few seconds to allow the person to prepare for the exam before it begins. You can also have the medical/dental professional demonstrate the procedure on the family member/care provider to model appropriate responses.
3. Allow sufficient time for the patient to process information. Many individuals who are deaf-blind require extra time to process information, and processing time may be increased if the individual experiences stress or anxiety.

For more information, check out:

Dental Care Every Day: A Caregiver's Guide. Published by the National Institute of Dental and Craniofacial Research, U.S. Department of Health and Human Services, 2004. [NIH Publication No. 04-5191]

First Impressions Module 2: Grooming. Videotapes and teachers' guides published by James Stanfield Publishing Co., Santa Barbara, California. [www.stanfield.com]

Perspectives of Dentists, Families, and Case Managers on Dental Care for Individuals with Developmental Disabilities in Kansas, by Amanda Reichard, H. Rutherford Turnbull, and Ann P. Turnbull. From the August 2001 issue of *Mental Retardation*, the journal of the American Association on Mental Retardation (Vol. 39, Number 4, pages 268–285).

Practical Oral Care for People with Developmental Disabilities. Published by the National Institute of Dental and Craniofacial Research, U.S. Department of Health and Human Services, 2004. [NIH Publication No. 04-5196]

Revised (2006) from *Strategies for Successful Medical Appointments for Individuals with Deaf-Blindness* (1996) by Susan Sternberg-White, former CDBS Project Coordinator.



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Estrategias para una Cita Médica o Dental Exitosa para Individuos que son Sordo-Ciegos

por Maurice Belote, CDBS Coordinador de Proyecto

Muchos individuos que son sordo-ciegos, tienen necesidades médicas que pueden requerir citas médicas frecuentes. Estos individuos también requieren cuidado dental regularmente que pueden también verse complicados por problemas físicos o de salud. Las visitas médicas o dentales pueden causar mucho temor para la persona que está recibiendo el tratamiento si los procedimientos no se esperan o no se entienden. Conforme el individuo que es sordo-ciego se va atemorizando, él o ella puede expresar miedo mediante comportamientos (ejemplos: berrinches, comportamiento agresivo, postura rígida del cuerpo, etc.) los cuales harían difícil el examen o el procedimiento. Las visitas pueden ser también muy frustrantes para las familias y las personas proveedoras de cuidados que ayudan durante los exámenes conforme tratan de explicar y manejar el comportamiento expresado.

Los puntos siguientes son algunas guías generales para promover experiencias exitosas y positivas durante citas médicas o dentales. Se sugiere que los familiares y los proveedores de cuidado revisen estas guías con los profesionales de salud cuando se haga la cita o cuando lleguen a la oficina. Una copia de esta hoja de datos se le puede dejar al personal médico o dental para informarles de las necesidades de sus pacientes que son sordo-ciegos. [Por favor tome nota de que estas ideas representan lo que podría considerarse una visita médica o dental ideal y que cada estrategia puede que no sea posible en cada situación.]

Sugerencias para profesionales

1. Trate de localizar un profesional médico o dental que tenga experiencias con personas sordo-ciegos. Si necesita una referencia, llame a los Servicios de California para la Sordo-ceguera (CDBS) al 1-800-822-7884; un especialista en familias de CDBS pudiera conectarlo con alguien que tenga información acerca de proveedores locales.
2. Llame al personal del médico o dentista antes de la visita para hacerles saber que esperar (por ej., dificultad para esperar, vocalizaciones fuertes y/o inusuales; comportamientos difíciles, etc.)
3. Si la familia o el personal médico o dental pueden arreglarlo, dele la oportunidad a la persona que es sordo-ciega de visitar la oficina médica o dental antes de la cita para que así él o ella se familiarice con el proveedor, con el personal de la oficina, el equipo, los olores, los sonidos, etc. Identifique claves-nombre o señas para algunas personas clave que estarán proveyendo los servicios dentales o médicos. Esta visita antes de la cita da la oportunidad de obtener muestras de los instrumentos que se pueden usar en juegos de actuación o juegos donde se asume un rol (ver la siguiente recomendación).
4. Proporcione la oportunidad de jugar a actuar o a asumir un rol antes de la cita médica o dental. Cuando sea apropiado de la oportunidad a la persona que es sordo-ciega de ser el proveedor y use las muestras de los instrumentos en otras personas (ej., familiares, maestros, compañeros de clase etc.) Permita oportunidades para que los compañeros hagan lo mismo con la persona que es sordo-ciega. Haga la experiencia relajada y divertida, y use esta actividad de actuación para reforzar el lenguaje que se usaría durante la visita médica o dental.
5. Traiga algo para que la persona haga durante los períodos de espera en la oficina.
6. Si el individuo tiene algún objeto favorito que pueda sostener o tocar durante el procedimiento, traigalo a la cita. Este podría dar al paciente algún nivel de bienestar y seguridad que lo ayudará durante el procedimiento.
7. Traiga los registros médicos de la persona para disminuir la repetición del historial, la espera de que les manden los archivos y exámenes médicos duplicados innecesarios. Incluya las direcciones y teléfonos de todos los proveedores de servicios.

La hoja de datos de Los Servicios de California para la Sordo-Ceguera (CDBS) son usados por ambos, familias y profesionales sirviendo individuos con sordo-ceguera. (ejemplo, personas que tienen problemas combinados de visión y audición) la información aplica a estudiantes desde su nacimiento hasta la edad de 22 años. El propósito de la hoja de datos es dar información general en un tema específico. Más información específica para algún estudiante en particular se podrá proveer a través de asistencia técnica disponible de parte de CDBS. Esta hoja de datos también está disponible en Inglés.

8. Traiga información acerca de la condición médica específica de la persona, si es que los profesionales médicos o dentales son nuevos o no son están familiarizados con el síndrome o condición en particular (ejemplo, Síndrome de Rubeóla Congénita, Síndrome de CHARGE, etc.).
9. Cuando sea posible, presente a cada uno de los profesionales médicos o dentales a la persona que es sordo-ciega antes de que estos lo toquen. Esto puede ser hecho con una señal de su nombre, clave de su nombre, un objeto concreto de referencia o un olor distintivo.
10. Hágle saber a la persona cómo está llendo el procedimiento. Dígale también que pasará después y cuáles son las razones del exámen en particular.
11. Modele y recompense el comportamiento de cooperación, la espera, la confianza, la postura del cuerpo relajada y de aceptación.
12. Si los profesionales médicos o dentales lo solicitan, proporcíóneles retroalimentación acerca de sus interacciones con el paciente y con el familiar o proveedor de cuidado (por ejemplo, la terminología usada, los modales para atender al paciente, el tono emocional y las ganas de trabajar con ustedes, etc). Esta información será de mucho valor para que los profesionales interactúen positivamente en el futuro con personas con sordo-ceguera.
13. Premie al paciente y a usted mismo seguidamente del proceso médico o dental. Pare de camino a la casa por algún obsequio, compre algún nuevo disco, vaya al cine, vaya a nadar a la alberca de la comunidad. Cualquier cosa que usted haga para premiarse. Como regla, nosotros no nos premiamos lo suficiente cuando pasamos por situaciones difíciles.
14. Coleccione objetos como un recuerdo de la visita para que esta sea discutida en el futuro, como cuando se está preparando para citas adicionales. La experiencia puede ser registrada en un “libro de experiencias” que pudiera incluir fotos, objetos, palabras impresas o en Braille o algún otro objeto que pueda ayudar al individuo a recordar el evento. Esté seguro de incluir el recuerdo del premio dado después de la visita, este pudiera servir como un motivante para citas en el futuro.

Sugerencias para profesionales

1. Caliente sus manos o los instrumentos antes de tocar a la persona sordo-ciega.
2. Dígale a la persona sordo-ciega lo que cada procedimiento implica antes de empezar el proceso. Esto se puede lograr dejando a la persona que examine el equipo por medio del tacto. Entonces usted puede tocar la parte del cuerpo de la persona que va a ser examinado con esa pieza de equipo. Pause por unos segundos para permitir que la persona se prepare para el exámen antes de que este empiece. Usted también puede decirle al profesional médico o dental que demuestre el proceso en alguien de la familia o en un proveedor de servicios y así modelar las respuestas apropiadas.
3. Permita al paciente suficiente tiempo para procesar la información. Muchos individuos sordo-ciegos necesitan tiempo extra para procesar información, y este tiempo de procesamiento se pudiera incrementar si el individuo esta experimentando estrés.

Referencias:

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Conclusion

There are many diverse groups that comprise the larger group we call Latinos. Considerations and strategies explained in this article will not apply to all the Latino families you work with. These strategies can, however, give you a place to start in the process of better understanding these families.



Latin America



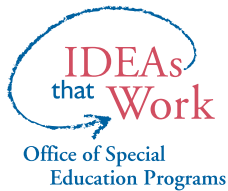
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