



Fact Sheet

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

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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 the 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).

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals who are deaf-blind. 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.

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.
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

15. Warm hands or instruments before touching the person who is deaf-blind.
16. 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.
17. 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, CDBS Project Coordinator.