Planning Guide for Dental Professionals Serving Children with Special Health Care Needs

USC University Affiliated Program
Childrens Hospital Los Angeles
California

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Planning Guide for Dental Professionals Serving Children with Special Health Care Needs

Principal Authors:
Beverly A Isman, RDH, MPH
Renee Nolte Newton, RDH, MPA

Project Coordinator:
Cary Bujold, MPH, RD

Project Director:
Marion Taylor Baer, PhD, RD

Graphic Designer:
Gayle Barrett


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Preface

Audience and Purpose
This Planning Guide has been developed for dental team members who wish to provide care to children with special health care needs, particularly those with developmental disabilities. Dental professionals will find the guide useful when scheduling appointments, promoting oral health with parents or other caregivers (anticipatory guidance), assessing dental needs, developing a realistic care plan, and providing preventive dental care.

Our goal is to foster better communication and understanding among dental professionals, parents, and other healthcare professionals to improve the oral health of children with special health care needs. Topics were chosen to address issues and concerns of parents and dental professionals, based on personal experiences that were related to us during interviews, focus groups, and surveys. Families have been shown to be the best advocates for their children’s unique needs, but often they feel frustrated when trying to find dental care. The content, therefore, revolves around family-centered care and creating opportunities for successful and productive appointments.

Using the Guide
This guide is not meant to be a self-instructional course about providing comprehensive care to children with special health care needs. Excellent references for further reading and opportunities for continuing education and clinical experiences are included at the end of the guide. This document does promote a framework for communication and tips for working with families to assure that appropriate, quality oral health care is provided both at home and in the dental office. Checklists, worksheets, information sheets and resource lists are included as tools for learning and communication. Some of the materials can be copied and used as handouts for parents.

The guide is divided into 6 sections. The first page of each section provides an overview of the materials in that section and their purpose. Materials are hole-punched for easy removal and reinsertion. We encourage you to use these materials and adapt them to your practice. Since the guide was developed with funding from the Maternal & Child Health Bureau, DHHS, HRSA, as part of the California Connections Project, please retain the logo and citations on materials that are copied. Any adaptations to the materials, however, will need prior approval (see the contact information on the next page).
Feedback on the Guide

A feedback form is included as an insert to solicit your input on the usefulness of the Guide in your practice. Your feedback and requests for additional copies can be faxed or mailed to:

Cary Bujold, MPH, RD
USC University Affiliated Program
Childrens Hospital Los Angeles
P.O. Box 54700, M.S. #53
Los Angeles, CA 90054-0700
Phone: (323) 669-2300
Fax: (323) 671-3842
Email: cbujold@chla.usc.edu

Specific questions about contents should be e-mailed to the primary authors:

Beverly A. Isman, RDH, MPH
E-mail: baisman@pacbell.net

Renée Nolte Newton, RDH, MPA
E-mail: rnnewton@pacbell.net

To learn more about the University of Southern California University Affiliated Program, access the website at www.uscuap.org.
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Andrea Azevedo, BDS, MPH
Maternal and Child Health Branch
California Department of Health Services
Sacramento, CA

Jay Balzer, DMD, MPH
Dientes! Community Dental Clinic
Santa Cruz, CA

Judy Boothby, RDHAP, BS
Dental Hygiene/Out and About
Sacramento, CA

Paul Casamassimo, DDS, MS
Department of Pediatric Dentistry
Ohio State University College of Dentistry
Columbus, OH

Robert Davenport, DDS, MS, MPH
Dental Disease Prevention Program
California Department of Health Services
Sacramento, CA

Gayle Duke, RDH, MEd
Children’s Medical Services
California Department of Health Services
San Diego, CA

Teran J Gall, DDS
California Dental Association
Sacramento, CA

Paul Glassman, DDS, MA
Department of Dental Practice
University of the Pacific School of Dentistry
San Francisco, CA
Robert Isman, DDS, MPH
Office of Medi-Cal Dental Services
California Department of Health Services
Sacramento, CA
Roberta Lawson, RDH, MPH
Dental Disease Prevention Program
California Department of Health Services
Sacramento, CA
Michael Martin, DMD, PhD
University of Washington School of Dentistry
Seattle, WA
Christine Miller, RDH, MHS, MA
Department of Dental Practice
University of the Pacific School of Dentistry
San Francisco, CA
Sue Sanzi-Schaedel, RDH, MPH
Multnomah County Health Department
Portland, OR
Edward Sterling, DDS
Nisonger Center
Columbus, OH
Elizabeth Van Tassell, DDS
Family and Hospital Dentistry
Petaluma, CA
Shanda Wallace, RDH
California Dental Hygienists’ Association
Stockton, CA
Joanne Wellman-Benson, RDH, MPH
The Dental Health Foundation
Sacramento, CA
Photos were provided by Wayne Grossman, DDS and Laurie Hanschu, DDS.
Planning Guide Feedback Form

1. Check all the types of dental care settings where you work.
   - Private general dental practice
   - Group practice
   - Dental or dental hygiene school
   - Dental specialty practice
   - Community clinic
   - Hospital
   - Other

2. What is your professional role?
   - Dentist
   - Dental Hygienist
   - Dental Assistant
   - Receptionist/Office Manager
   - Other

3. About how many children with special health care needs are in your practice?

4. Which of the following components of the Guide have you used in the practice? (check all that apply and circle the number that corresponds to their usefulness in your practice)

   - Providing family-centered care
     - Not useful
     - Of some use
     - Very useful
   - Getting to know me
     - 1
     - 2
     - 3
     - 4
     - 5
   - Dental office considerations checklist
     - 1
     - 2
     - 3
     - 4
     - 5
   - Performing the oral assessment for young children
     - 1
     - 2
     - 3
     - 4
     - 5
   - Oral conditions in young children
     - 1
     - 2
     - 3
     - 4
     - 5
   - Home care counseling and anticipatory guidance
     - 1
     - 2
     - 3
     - 4
     - 5
   - Getting Connected Oral Health
     - 1
     - 2
     - 3
     - 4
     - 5
   - Positioning
     - 1
     - 2
     - 3
     - 4
     - 5
   - Oral hygiene aids
     - 1
     - 2
     - 3
     - 4
     - 5
   - Dental health education materials
     - 1
     - 2
     - 3
     - 4
     - 5
   - In-office preventive dental procedures
     - 1
     - 2
     - 3
     - 4
     - 5
   - Behavior management considerations
     - 1
     - 2
     - 3
     - 4
     - 5
5. Are there other materials you would like to see developed that are not included in the Guide? Please describe.

6. As a result of having this Guide, what changes have you made in the office environment, or the way you interact with families of children with special health care needs?

7. If you want to be on a mailing list for additional materials or training on Oral Health and Other Healthcare Needs of Children with Special Health Care Needs, include your name, address and phone number in this space.

Please return this feedback form to:
Cary Bujold, MPH, RD
USC University Affiliated Program
Children's Hospital Los Angeles
PO Box 54700, Mail Stop #53
Los Angeles, CA 90054-0700
Section Overview
The materials in this section help to create a shared philosophy of care between families and the dental team to assure that the child receives appropriate dental care in a safe and caring environment, based on the needs of the child and family and the resources of the dental team.

Providing Family-Centered Care in Dentistry
A suggested philosophy of care for working with families of children with special health care needs is provided where the dental care system is responsive to the priorities and unique needs of each family, and the family members understand their rights and responsibilities as consumers of dental services.

Getting to Know Me
This form can be used to acquire a personal profile of each child and family as part of the assessment and relationship-building process.

Dental Office Considerations Checklist
This is a self-assessment tool for the dental team to determine how best to accommodate children with special needs in the dental office.
Families who have children with special health care needs are faced with many challenges in today’s healthcare systems. Dental care is an important piece of that system. Frequently, multiple agencies and providers are involved in the care of a child, making coordination of services important. Family-centered services and information can enable families to provide the best care for their child at home and to help you provide the best professional care in your office.

**What is family-centered care?**

*Family-centered care means that the healthcare environment and professionals are responsive to the priorities and choices of families with children who have special health care needs.* Recognize the vital role that all families play in ensuring the health and well-being of their children and acknowledge that emotional, social and developmental support are integral components of health care.

**What are some ways to assure that services are family-centered and to build a healthy parent-provider relationship?**

*Recognize parents as primary managers of their child’s health care.* Families bring their own expertise to their role as care managers since they are with the child every day and interact with all of the child’s healthcare providers. Involve parents in the child’s dental care by asking for and considering their opinions and responding to their concerns. Letting parents know that their input is important will build mutual respect.

*Consider flexibility in scheduling and facilitate any necessary referrals.* As much as possible, consider the family’s daily life priorities and the challenges of having a child with special health care needs. Ask about transportation and other child-care needs when scheduling visits. A child with special needs may have multiple healthcare appointments every week with different providers and therapists. Coordinated scheduling is important to families and may help to reduce “no show” appointments or cancellations. Scheduling enough time to accommodate the family’s needs and to answer questions will increase satisfaction and improve follow-up on recommendations. If referrals to dental specialists are necessary, personally make the referral and explain to the family what they should expect at the consultation. Review office policies and patient responsibilities with the family to clarify concerns and to determine if accommodations are needed.

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Provide information about other resources. Learn about other resources and support services in the community to increase your knowledge of children’s special health care needs. Examples include local school districts, public libraries, family resource centers, regional centers, local health departments, dental or dental hygiene schools, associations for children with specific health disorders, websites, or information and referral programs.

Be culturally responsive. Families have many diverse traditions and languages. If your office does not have bilingual/bicultural staff, AT&T provides translation services by phone to assist in appointment scheduling or with questions. Providing services in a language the family can understand is your responsibility if you accept federal or state funds as payment for dental services rendered. Families cannot be required to provide a translator, even if he/she is a relative. Untrained interpreters may not fully understand dental terms used and may omit information. Pertinent information about treatment or follow-up care also may be lost. Having dental health information written in the primary languages of most of your patients will help them learn to be more informed dental consumers and to practice preventive home care. One way to obtain materials is from community agencies who serve various ethnic groups or diverse patient populations. Often they will have experienced translators who can be helpful.

Include families in decisions about their child’s care. By being a member of the decision-making team and learning what choices they have, parents will be more inclined to follow through with treatment plans and recommendations. You can encourage parents to become active partners in this process by carefully explaining options for care. Encourage parents to ask questions and take notes or bring a tape recorder. Provide informational materials and a brief, easy-to-understand written summary of your recommendations for them to review with others involved in their child’s care. Using a home dental record card to record appointment dates, services provided, and follow-up or recall appointments needed will give them a permanent record of the child’s dental care and help them keep up-to-date with care.

Source: Institute on Family Centered Care, 7900 Wisconsin Ave., Suite 405, Bethesda, MD 20814 (301) 652-0281.
Getting To Know Me

Please complete this form with/for your child so we can better understand and meet your child’s unique needs. Bring it with you to your appointment. Thank you.

Child’s Name ___________________________ Nickname ___________________________

Date of birth ________________ Age ________________ Date today ____________________

Parent(s) Names ________________________________________________________________

Other regular caretakers (more than twice a week):

☐ Siblings
☐ Grandparents
☐ Other relatives
☐ Babysitter
☐ Daycare
☐ School programs
☐ Others

Current medications and any sensitivities to medications:

Adaptive aids:

Therapies I receive (e.g., occupational or physical therapy):

Special educational programs:

Other supportive services that help me:
Ways I communicate:

Some of my strengths:

Things that make me smile or make me feel good (e.g., favorite toys, phrases):

Things that might bother me in the dental office:

My behaviors or conditions you might find challenging in the dental office:

How my family deals with these behaviors or how they can help you deal with them:

Past experiences with dental care:

Problems or questions my family has about home oral hygiene care:
Meeting The Needs Of Families With Children Who Have Special Health Care Needs

Special health care needs refers to a variety of conditions. Some children may need extra help or adaptations when receiving dental care. Providing information about your office and staff will help families decide if you can accommodate their child’s unique needs. Use this checklist as a starting point to analyze how you can accommodate special needs or where you may encounter difficulties. Rationales for the questions are given. Resources for increasing your knowledge and skills are included in the Bibliography and Other Resources Section.

- Is your office accessible to people in wheelchairs?
  The Americans with Disabilities Act requires reasonable accommodations or an appropriate referral if the accommodation is a hardship.

- If parents need help getting their child into the office from the parking lot, is there someone on the staff who can provide assistance?
  Parents are grateful for a little help when carrying items, assisting with adaptive equipment or carrying the child. They should be encouraged to call ahead to alert staff that help is needed.

- Do all staff members know how to perform safe wheelchair transfers and use a transfer board?
  Children prefer to be transferred by someone they trust, so discuss the most effective transfer method with the parent and demonstrate that you are aware of the principles of safe transfers. These techniques should be practiced by all staff.

- Do the dental chairs have movable armrests to facilitate easy access?
  It is difficult to lift children over armrests or move them into the chair if they are wearing leg or back braces.

- Can a wheelchair fit parallel to the dental chair in most of the operatories?
  Performing exams and some preventive care with children in their wheelchairs sometimes is preferable to a transfer, particularly if the wheelchair can be adjusted. Transfers are also more difficult if the operator is too crowded to align the wheelchair close to the dental chair.

- Which type of delivery system do you use?
  - Front—over the patient
  - Mobile carts
  - Fixed—rear delivery
  - Combination
  - Other_____________________________
  Children who have attention deficit hyperactivity disorder, or who have uncontrolled muscle reflexes, may injure themselves or scatter instruments on an “over-the-patient” delivery system.

- Would any of your policies on late arrivals or cancellations adversely affect families who have children whose health or developmental needs may be unpredictable?
  Children who experience frequent medical problems or hospitalizations, or who have multiple therapy appointments, may need special arrangements for appointments.
How are the exam/treatment rooms arranged?

- Open bay with multiple chairs
- Private rooms
- Combination
- Other

Children with sensory impairments or attention deficits may be easily distracted.

Can the x-ray equipment reach low enough to accommodate very young children or children in wheelchairs?

Trying to take radiographs on young children is challenging in itself, but equipment limitations can cause unnecessary frustration; assess the need for adaptations such as booster seats.

Do you have panoramic film capability?

Some children may not be able to bite effectively to hold a bitewing or periapical x-ray. However, not all children will be able to hold still long enough for completing a panorex.

Are staff versed in alternative radiographic techniques, e.g., lateral jaw, snap-a-ray?

Alternative techniques are available to compensate for a child’s inability to fully cooperate; parents may also assist with stabilization if lead shielding is available.

Are parents allowed to be in the operatory with the child?

Involving the parents in at least some of the care will increase their understanding of the process and may reduce anxiety on the part of the child. Parental knowledge is particularly important when working with medically-compromised children, especially if they have frequent seizures, or swallowing or breathing problems.

Do you have a policy on use of patient restraint or aids for patient stability?

Use of any techniques for stability or that restrict movement require informed consent through thorough explanation to parents (including the rationale and timeframe for their use). Their use should be determined by an assessment of individual need.

What is your informed consent process for:

- Examination?
- Treatment?
- Behavior management techniques?

Parents who receive thorough and clear explanations of their child’s needs, and participate in decisions for care, will be more comfortable giving informed consent for care, particularly when special techniques are needed.

Do you send any health history or other forms home for completion prior to the initial appointment?

Parents who have children with complex medical needs will appreciate the extra time to complete the forms accurately and to gather copies of any medical records that might be helpful to you in caring for their child. Accurately completed forms also will save you time.

Would you schedule an orientation/initial consultation session with a family if they requested one?

Because parents have contact with so many medical and other professionals, they want to know that their child is going to receive the highest quality care from a provider who feels comfortable treating their child, and staff who understand his/her special needs. An initial interview will allow parents to see the office environment, enable the dental team to meet the child, and everyone can ask questions.
Are you able to schedule appointments to allow for flexible staffing and assistance if needed? For example, the dental hygienist may need a dental assistant to help place sealants or take radiographs, or two staff may be needed for a few minutes to assist with a wheelchair transfer.

What type of payment methods/arrangements do you accept? Are you aware of any community resources for financial coverage for children with special needs who can’t afford dental care? Parents should learn this information before the appointment to see if they qualify for any special programs, if they need to budget ahead to cover expenses, or if dental procedures require pre-approval.

Do you have an individualized recall system for exams/preventive appointments? Children with certain medical conditions may need more frequent recall intervals if they are on special diets, have compromised immune systems, or are tube fed.

Is there any coverage for dental emergencies at night or on the weekends? Some children may experience oral injuries from seizures, falls or other causes. Parents need to know when and where to take the child for an oral injury.

Do you provide any health education, oral screenings or dental services to children with special needs at programs in the community such as regional centers or schools? Services such as these may help to detect oral problems early and facilitate appropriate referrals for care. Teachers and caregivers will also appreciate your efforts to reduce transportation barriers for the children and learn something about their programs.

Have any of the staff members received special training in working with children with special health care needs? Continuing education courses and self-study manuals are available to increase knowledge and skills of all dental team members.
Section Overview
The materials in this section are intended to be used when conducting the initial oral health assessment and any subsequent appointments for preventive procedures. They will help you design approaches for effective homecare strategies, developmentally appropriate anticipatory guidance, and in-office prevention programs. Some of the materials are included as inserts at the end of the Guide.

Performing the Oral Assessment for Young Children with Special Health Care Needs
Use as a guide for conducting an oral assessment specifically for young children who have developmental disabilities or genetic disorders.

Oral Conditions in Young Children with Special Health Care Needs (Insert)
Review these conditions that might be seen when examining young children with special health care needs. Color photographs of oral conditions are included with counseling recommendations.

Home Care Counseling and Anticipatory Guidance for Oral Health
This information may be used by dental professionals when counseling families about oral health. "Getting Connected" materials (included as inserts) may be copied and given to parents/caretakers.

Positioning (Insert)
A handout reproduced from a packet produced by the American Dental Hygienists’ Association shows a variety of positions to use in the home when providing oral hygiene care to people with developmental disabilities.

Oral Hygiene Aids for Children with Special Health Care Needs (Insert)
This teaching handout shows color photos of commercially available oral hygiene aids that may meet the needs of children at various ages and with various motor skills. This handout can help parents select appropriate supplies.

Dental Health Education Materials
Considerations for using print or audiovisual materials during counseling and a list of selected materials are included.

In-Office Preventive Dental Procedures
Considerations and adaptations are included for providing preventive dental procedures in the dental office setting and establishing appropriate recall intervals.
Most pediatric dentists recommend that a child be seen for a dental visit by the first birthday to initiate a program of effective preventive measures, provide anticipatory guidance, and decide the periodicity of subsequent visits to assess risk for dental disease or growth problems. Many dental professionals feel it is useful to have the parent present during the oral inspection to maximize communication and understanding.

**Parent Interview**

Children with special health care needs may require a more detailed interview with the parents to acquire a medical history that enables provision of appropriate anticipatory guidance for oral health and safe, appropriate dental care in the office setting. Include questions on:

- **Prenatal, natal and neonatal history:** this might be helpful in explaining any dental abnormalities or immature motor reflexes.
- **Developmental history:** a brief overview of the parents’ perceptions of the child’s development helps correlate dental growth and development with general developmental milestones.
- **Feeding history:** this is important to determine how difficult the baby was to feed; delays in progression of feeding skills; if special formula, tube feeding or therapeutic diets were needed; food likes, dislikes and allergies; and potential risks for development of dental caries.
- **Medical history:** ask questions about history of illnesses, medications taken that might have dental sequelae, history of any surgeries, other medical care related to the child’s special health problems.
- **Dental history:** try to gain insight into any teething problems, oral lesions or trauma, home care practices, and previous visits to dental offices.
Oral Inspection

The oral inspection can be conducted with a tongue depressor, mouth mirror, or a small child’s toothbrush, in addition to gloves and an adequate light source. For very young children, this may be accomplished using the two-person, knee to knee position, rather than placing the child in a dental chair.

The oral inspection should include assessment for conditions such as:
- Enamel hypoplasia and enamel demineralization (white spots)
- Dental caries
- Developmental anomalies, delayed tooth eruption and malocclusion
- Diseases of the gingiva and other soft tissues
- Oral reflexes and oral sensitivity
- Oral injuries

Enamel Hypoplasia and Enamel Demineralization

Children with low birthweight, developmental delays, or certain genetic syndromes appear to be at increased risk for enamel hypoplasia. Enamel hypoplasia seems to be a predisposing factor for dental caries, especially in the maxillary incisors and primary molars. Hypoplasia usually appears on the middle or occlusal third of the teeth, whereas demineralization from poor oral hygiene and an acidic oral environment occurs most often near the gingival line. Demineralization often is characterized as white spot lesions that are best seen by “lifting the lip”.

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- Dental Caries
  - Wipe the teeth with a 2X2 gauze and retract the lips and cheeks. Look for obvious decay and/or erosion that may result from frequent reflux, altered salivary flow, cariogenic diets, or inappropriate feeding practices.
  - Early childhood caries occurs most often on the facial and lingual surfaces of the maxillary teeth.

- Developmental Anomalies, Delayed Tooth Eruption and Malocclusion
  - During the extraoral examination, note any craniofacial anomalies or facial asymmetry. Most children with cleft palate/cleft lip are under the care of a multidisciplinary team of professionals right after birth, since treatment consists of a sequence of corrective surgeries and therapies.
  - Moving intraorally, check for malocclusion in the primary teeth that may create problems in the permanent dentition. Malocclusions occur frequently in children with developmental problems (more than 80 craniofacial syndromes exist). Hypoplasia of the maxilla, micrognathia, and prognathia are especially prevalent.
  - Delayed eruption of teeth is seen in children with certain genetic disorders, particularly Down syndrome, or in children with general developmental delays that involve the oral musculature. Check the sequence of eruption to determine if the sequence is normal and just delayed, or if there is a more isolated eruption problem.
  - Note any deviation or morphologic defects in teeth that may be due to growth disturbances, muscle dysfunction, Down syndrome, oral clefts, hypothyroidism, ectodermal dysplasia or other conditions that are associated with variations in the number, size, and shape of teeth.
  - Supernumerary teeth, as well as fused and geminated teeth may be seen. Anodontia and hypodontia also are associated with genetic disorders and syndromes. Damage to the developing dentition can be caused by laryngoscopy and endotracheal intubation in babies who are pre-term or who experience other problems after birth.
• **Diseases of the Gingiva and Other Soft Tissues**
  
  Examine the gingival tissue noting any inflammation, bleeding, infection, tissue overgrowth, or tissue destruction from self-injurious behavior.

  Early severe gingivitis or early periodontitis can occur in children who have impaired immune systems or connective tissue disorders and inadequate oral hygiene.

  Gingival overgrowth is a side effect of medications such as phenytoin sodium, calcium channel blockers, and cyclosporine. Look for any signs of superimposed infection.

  While inspecting the soft tissues, also check for signs of other infectious diseases such as herpetic gingivostomatitis, herpes labialis, or fungal infections, especially if the child is on regular antibiotic therapy, or if you suspect child abuse or neglect.

• **Oral Reflexes and Oral Sensitivity**
  
  Assess for oral hypersensitivity, excessive gagging, swallowing difficulties or oral hypotonicity. Any of these factors can interfere with optimal feeding, toothbrushing and in-office preventive dental care. Food adherence and retention in the mouth due to food consistency, inadequate oral hygiene or abnormal muscle control are risk factors for dental disease.

• **Oral Injuries**
  
  Children who experience some types of seizure disorders, abnormal protective reflexes, muscle incoordination, behavioral disorders, or attention deficit disorders are at high risk for facial and intraoral trauma, some of which may be self-inflicted. Look in the mouth for any fractured, intruded, extruded, missing or mobile teeth, lacerated frenums and scar tissue. Lip and facial lacerations are common and can easily become infected.

  Check the hands for evidence of repetitive finger sucking or biting.

  Children with developmental disabilities are at risk for child abuse if the caretaker is overwhelmed, becomes frustrated with the child’s behavior, and is unable to understand the child’s limitations. Up to 50% of abused children suffer injuries to the head and neck.
Anticipatory guidance in this document refers to oral health counseling based on developmental stages in a child’s life. Although in most children it is based on chronological age, in children with developmental disabilities or delays, it is based more on an overall assessment of the child’s growth and development and level of functioning in activities of daily living. Parents frequently report that they receive little information about their child’s dental growth and development and that they often don’t feel confident in performing oral hygiene care.

The best way to involve parents and to increase their understanding and confidence is to explain what to look for and what you see in the child’s mouth. Then demonstrate appropriate oral care skills. Ask the parents to demonstrate how they clean and inspect their child’s mouth. Inquire about any problems they encounter and brainstorm together to arrive at some realistic strategies for home care. Level of comfort and the type of problems encountered will change as the child progresses through various developmental stages.

**Desired Outcomes**

- Parents are informed of oral development and teething issues.
- Parents are informed of, and practice, preventive oral health care, including brushing child’s teeth with pea-size amount of fluoride toothpaste.
- Child is given increasing responsibility for self-care as development and motor skills allow.
- Child rides in appropriate and properly secured car safety seat.
- Child’s environment is safeguarded to protect against oral/facial injuries; protective gear is worn as needed.
- Child receives appropriate fluoride exposure.
- Child has no active carious lesions.
- Child has healthy oral soft tissues.
- Child has functional occlusion.
- Child receives regular dental care.
- Family is satisfied with the child’s care and their relationship with the dental team.

Anticipatory Guidance

Teach parents to “lift the lip” to check for white spot lesions or early childhood caries as well as oral lesions or dry tissues from mouthbreathing. Use colored photos to show various conditions (see the “Oral Conditions” insert in this guide.)

Provide fluoride based on an assessment of the child’s source and consumption of drinking water; counsel parents about proper use and storage.

After the first dental visit, establish periodic recall intervals based on the child’s needs, parental confidence in home oral care practices, and risk for future dental problems.

Review ways to prevent dental injuries and how to handle common dental emergencies, especially the loss or fracture of a tooth, or a severe oral laceration or infection from biting the tongue or lip.

Provide parents with a phone number for dental emergencies after office hours.

Discuss the benefits of dental sealants in preventing tooth decay.

Demonstrate use of a pea-sized amount of toothpaste and how to effectively brush all the teeth. Developmental skills will determine the age at which a child can effectively perform oral hygiene skills.

Share the inserted handout on “Positioning” for toothbrushing with parents. Help the parents decide what oral hygiene aids will be most appropriate for their child. Try to recommend ones that can be purchased in most stores (see the insert “Oral Hygiene Aids” in this guide.)

If a child regularly sucks a pacifier, fingers or hands past age 4 or 5, begin to intervene to help the child break the habit.

Coordinate any dietary recommendations with the primary care medical provider and others involved in the child’s care. It is particularly important to coordinate recommendations on appropriate bottle feeding (if used) with special dietary regimens for specific nutritional or feeding disorders to prevent early childhood caries.

If oral motor dysfunction interferes with home oral care or delivery of dental services, consult with other members of the child’s multidisciplinary health care team (e.g. occupational or physical therapist, nutritionist or early childhood specialist).
Every person learns differently; most learn using multiple modalities e.g., seeing, hearing, doing. It is important to gear health education approaches to the person’s best ways of learning. If one or more modalities are impaired, the task is even more challenging. Assessing learning interest and modalities is a key component to any health education effort.

Many families of children with special health care needs have related that dental health education materials or approaches used in dental offices or school programs were not appropriate for their child’s needs and abilities and didn’t address their questions. Consider the following factors when selecting or designing materials for these families.

- Family members and children of different ethnic groups are portrayed.
- Photos or drawings include children with special needs.
- Materials are colorful, modern and attractive.
- The visual layout is easy to follow and maintains interest.
- Information is short and concise, with non-technical language.
- Important points are highlighted.
- Language and language level are appropriate for the family.
- The health messages reflect current dental science and are not outdated or inaccurate.
- The content reflects the office philosophy.
- Rationales for recommendations are included.

**Selected Brochures, Pamphlets**

Selected resources for parents are included because they are specific to children with special health care needs or they contain good information on children’s oral health care.

Brochures on infant and children’s oral health are available at $40.00 for 100 from:

American Society of Dentistry for Children
875 North Michigan Avenue, Suite 4040
Chicago, IL 60611
Phone: 312-943-1244
Fax: 312-943-5341
http://cidental.creighton.edu/asdc
Information Sheets — Just for Parents:
California Society of Pediatric Dentistry
www.cspd.org

ARC Oral Health Care Packet: Preventing Dental Disease in Children with Disabilities — 10 page folder with at-home tips and techniques on oral health care for children with disabilities. Easy to copy for using with parents. 1-24 copies @ $2.00 each or 25+ copies @ $1.25 each from:
American Dental Hygienists’ Association
444 North Michigan Avenue, Suite 3400
Chicago, IL 60611
Phone: 800-243-2342, Press #2
Fax: 312-440-8929
www.adha.org/shopping/patient.htm

Dental Care for Special People — Covers oral hygiene care, sealants, medication effects, and more. 16 page brochure, 50 copies for $23.00 or 100 copies for $41.00 from:
American Dental Association
PO Box 776
St Charles, IL 60174
Fax: 630-443-9970
www.ada.org

Protect Your Child’s Teeth! Put Your Baby to Bed With Love, Not a Bottle — available in English, Spanish, Chinese, Vietnamese, Cambodian, Laotian, Thai, $10.00-15.00 depending on quantity from:
The Dental Health Foundation
520 Third Street, Suite 205
Oakland, CA 94607
Phone: 510-663-3727
Fax: 510-663-3733
www.dentalhealthfoundation.org

Special Athletes, Special Smiles
Fulfillment Inc.
1123 Pearl Street
Brockton, MA 02401
Phone: 508-583-6385
Fax: 508-580-9792

Overcoming Obstacles to Dental Health. A guide to good oral health for persons with special needs. Available from:
University of the Pacific Dental School
Special Needs Program, Room 101
2155 Webster Street
San Francisco, CA 94115
Phone: 415-929-6428
Fax: 415-929-6654
Seal Out Dental Decay; A Healthy Mouth for Your Baby
Available from:
National Institute of Dental Research
P.O. Box 54793
Washington, DC 20032
www.nidr.nih.gov

Dental Care for Your Baby — multiple brochures:
American Academy of Pediatric Dentistry
211 E. Chicago Avenue, Suite 700
Chicago, IL 60611
Phone: 312-337-2169
Fax: 312-337-6329
www.aapd.org

This national clearinghouse may have additional materials:
National Maternal and Child Health Clearinghouse
2070 Cain Bridge Road, Suite 450
Vienna, VA 22182
Phone: 703-356-1964
Fax: 703-821-2098
www.ncemch.org/oralhealth

Oral Care for Persons with Disabilities and Their Caregivers. Set of six booklets for $14.00.
University of Washington School of Dentistry
Dental Education in Care of the Disabled (DECOD) SC-63
Seattle, WA 98195
Phone: 206-543-5448
Fax: 206-685-8412

Videos
Preventing Tooth Decay: Infants and Toddlers — available in many languages for $28.50 from:
Guninder C Mumick
Multicultural Health Education Consultant
Vancouver Health Board
1060 West 8th Avenue
Vancouver, BC V6H 1C4
Fax: 604-734-7897

Overcoming Obstacles to Dental Health (See previous citation under Pamphlets.)
Healthy Smiles for Children with Special Needs — 12 minute video, stories told by three parents; ABC’s of Infant Oral Health — video, poster and reference cards. AAPD. (See previous citation under Pamphlets.)
Preventive dental care can be a pleasant and rewarding experience for a child with special health care needs if enough time is taken to establish trust and to provide an orientation to the dental office environment, equipment and procedures. Noise may startle children with sensory impairments or those who have impaired ability to understand the procedures. Introduce all instruments and equipment before using them. Demonstrating on the child’s or your fingernail or on a doll will help the child to understand the procedure. Two people working as a team (e.g., dentist and dental hygienist; dental hygienist and dental assistant) sometimes are needed to accomplish preventive procedures in an efficient and comfortable manner with some children.

Involving parents in the child’s care while in the operatory requires good communication before, during and after you provide preventive services. Decisions about appropriate ways to involve the parents are based on discussions before beginning the procedures and on observations of parent/child interactions.

Because each child’s needs are unique, a preventive plan should be individualized and reassessed on a regular basis. Dental staff may wish to develop a checklist for parents of recommended in-office and home-care preventive measures, as well as key messages to reinforce the importance of regular care. The following preventive measures should be considered when developing a prevention plan.

**Fluorides**

*Fluoride in Drinking Water and Fluoride Supplements*

Determination of systemic supplementation of fluoride is made on the basis of knowledge of the child’s drinking water sources and consumption.

Children with physical or mental challenges may be dependent on others for their water intake. Even if the drinking water is fluoridated, actual intake may be limited.
If recommending a prescription for fluoride tablets, consider whether the child can chew, swish or spit and if parents understand the proper dosage and frequency. Discuss the difference between “a dropperful” and “a drop” if prescribing liquids. Liquids may be easier for young children with oral motor problems as drops can be placed directly in the mouth.

The following table contains the dosage schedule (approved in April 1994 by the American Dental Association Council of Scientific Affairs) for fluoride supplementation as recommended by the American Academy of Pediatrics, the American Dental Association, and the American Academy of Pediatric Dentistry.

### Systemic Fluoride Supplement Dosage Schedule

*Fluoride Ion Level in Drinking Water (ppm)*

<table>
<thead>
<tr>
<th>Age</th>
<th>&lt;0.3 ppm</th>
<th>0.3-0.6 ppm</th>
<th>&gt;0.6 ppm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 6 months</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>6 months to 3 years</td>
<td>0.25 mg/ day**</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>3 to 6 years</td>
<td>0.50 mg/ day**</td>
<td>0.25 mg/ day**</td>
<td>None</td>
</tr>
<tr>
<td>6 to 16 years</td>
<td>1.0 mg/day</td>
<td>0.50 mg/ day**</td>
<td>None</td>
</tr>
</tbody>
</table>

*1.0 ppm = 1 mg/liter
**2.2 mg sodium fluoride contains 1 mg fluoride ion

**Topical Fluorides**

Topical gel or foam applications may be especially beneficial for children who are unable to use home oral rinses with fluoride or who are at high risk for caries development. Adaptations may be needed for children who have oral motor dysfunction (abnormal reflexes or muscle control) or oral hypersensitivity (over-reaction to touch, taste or smell).

- Gel or foam applied in trays requires frequent use of suction to prevent choking, excessive drooling or aspiration.
- The trays may trigger hyperactive bite or gag reflexes; brushing on the gel or foam for the same period of time with use of suction may be more successful.
- Experiment with the taste of the product with the child before application to assure acceptance.
Oral rinses generally are only recommended for children who have adequate oral motor control for “swishing and spitting”. Many children with oral motor dysfunction tend to swallow the rinse. Brushing on the rinse or use of brush-on gels is more appropriate for these children. Alcohol-free rinses should be used with children.

Demonstrate to parents or other caretakers applying only a dab of toothpaste (pea-size) and ask them to closely supervise brushing to prevent ingestion of toothpaste. If the child persists in swallowing the toothpaste, consider using a non-fluoride toothpaste or one made just for very young children.

Fluoride varnishes are easy to apply and becoming more accepted as preventive agents by the dental community. They do not necessarily require application in the dental office, and may be placed at community-based programs such as Head Start, WIC, or a regional center for the developmentally disabled.

Fluoride varnish should be applied at intervals of three to six months in children who are at increased risk for early childhood caries. Currently, use of fluoride varnish in caries prevention is considered “off label” use by the FDA, since varnishes originally received approval for use as a cavity varnish. Off label use does not mean that it is illegal or unethical to use varnishes as preventive agents. The Federal Food, Drug and Cosmetic Act doesn’t limit the manner in which physicians or dentists may use approved drugs.

(DFA. Use of approved drugs for unlabeled indications. FDA Drug Bulletin. April 1982.)

Dental Sealants
If children are at risk for developing dental caries due to dietary factors, salivary dysfunction, or tooth anatomy, they may benefit greatly from sealants and may be cooperative since sealants don’t require placement of a rubber dam or an injection.

Children who severely brux their teeth (e.g., from severe mental retardation, cerebral palsy or autism) may not be candidates for sealants because of the flattened occlusal plane.

Maintaining a dry working field may be difficult with some children who have oral motor dysfunction. Efficient and effective suctioning is essential. Use the air syringe cautiously as it may trigger a startle reflex.
Antimicrobials for Gingivitis
Some children with diseases/disorders such as leukemia, kidney failure, immune deficiencies or Down syndrome may experience moderate to severe gingivitis or periodontitis. They may also experience more fungal or other opportunistic infections. These may interfere with chewing and nutritional intake.

Oral antimicrobial rinses generally are not appropriate if the child can’t swish or spit. The alcohol content also may be a contraindication for children. Concentrations that can be swabbed, brushed, or sprayed onto the gingiva are more effective.

Systemic antibiotics for gingivitis should be used with caution if the child is on multiple medications or frequent antibiotics for other reasons. Medical consultation may be indicated.

Scaling and Prophylaxis
Some children who have special health needs develop excessive calculus. Causes can include mouthbreathing, inadequate salivary flow, metabolic disorders, kidney failure, tube feedings, oral motor dysfunction or inadequate oral hygiene. Scaling with hand or power instruments may be needed. Meticulous suctioning is needed to prevent aspiration of water or fragments of calculus.

If oral debris is heavy, a very light rubber cup polishing may be useful to remove gross layers of debris. Routine rubber cup prophylaxis in very young children are not recommended for general plaque removal, as they remove the outer fluoride-rich layer of enamel that is important for the process of caries prevention and remineralization. Simple toothbrushing is as effective for plaque removal and is generally more acceptable to children. Toothbrushing also reinforces the method used for home care.
When Specialized Treatment Techniques Are Needed

Section Overview
The materials contained in this section address the need for specialized dental care and may be used by the dental provider in preparing children and their families for such care.

Behavior Management Considerations in Treatment of Children with Special Health Care Needs
A brief description is included of some of the techniques that may be used for stabilization and behavior management by general dentists but most commonly by the dental specialist. Parents often do not understand the purpose for the use of these management options and will need a clear explanation when and if they are used.

Sample Consent Form
An example is included of a consent form to be signed for a child who will require stabilization techniques. This is an acknowledgment by the parents that they have been informed of and agree with the techniques that will be used and why they are used.

Dental Specialty Resources for Children with Special Health Care Needs
This form can serve as a resource list to use when arranging for and coordinating a child’s specialty care.

Preparing Children and Their Families for the Hospital Dental Experience
This outline may be used when discussing some of the issues involved with hospitalizing a child for dental care.
Behavior Management Considerations in Treatment of Children with Special Health Care Needs

General Considerations
Behavior management represents a continuum of interaction for the purpose of establishing rapport, promoting positive behavior in the dental office setting, and performing treatment effectively, efficiently and safely. All management decisions must be based on an evaluation, weighing benefit and risk to the child. Decisions regarding treatment and management cannot be made unilaterally by the practitioner, but must involve the parents, and, if feasible, the child. This partnership is necessary to ensure informed consent, and an understanding of all procedures with their risks and benefits, before the management techniques are initiated.

Adverse behavior for dental care can result from fear or lack of understanding of dental procedures, personnel or the dental office environment. It can be a consequence of immature development or impaired development. Lack of stability or muscle control or impulse control also can create behavior that can endanger the safety of the patient or the dental provider during dental treatment. Communicative management using voice control, nonverbal communication, tell-show-do technique, positive reinforcement, and distraction are the preferred methods. Comprehensive dental services for some children who are disabled or who are very young require the use of more complex management techniques. These techniques should be selected on an individual basis, according to what treatment is needed and the child’s health/physical status. They should only be used after other behavioral management techniques have proven ineffective. These techniques are used to minimize the risk of injury to the patient and to the provider. Adequate provider and staff training (and certification in some cases) is critical to proper use of these techniques.

Various national organizations periodically issue guidelines on behavior management considerations for dental care in the office setting as well as in residential facilities. Citations for locating some of these guidelines are listed in the Bibliography section of this Guide.
Informed Consent

An important component of behavior management is informed consent. Merely having a signature on a form is not informed consent. In general, the doctrine of informed consent requires that informed consent be obtained before a health professional may legally provide treatment. Informed consent implies two separate responsibilities:

▲ Disclosing information to the patient/parent
▲ Obtaining the patient’s/parent’s consent before administering treatment.

The following elements constitute informed consent:

▲ Information, including:
  a. Reasons for treatment
  b. Diagnosis
  c. Prognosis
  d. Nature of care and treatment
  e. Alternatives
  f. Risks
  g. Expectancies of success
  h. Possible results if no care or treatment is undertaken.

The patient also has a right to know which option the health care provider recommends. The health care provider has no obligation to present options which he/she considers to be unacceptable.

▲ Comprehension: The health professional must actively engage the patient/parent in a verbal exchange to clarify issues, ask/answer questions, and verify the patient’s/parent’s comprehension. This should be done in the family’s primary language, with the assistance of a trained interpreter if needed.

▲ No deception or coercion can be used to gain consent.
▲ The person making the decision must be considered “competent” to understand the information and to make a decision.
▲ The patient/parent must clearly communicate his or her choices.

An example of a behavior management form that can be reviewed and signed by parents after the provider has thoroughly discussed the options is included in this section of the Guide. Including a photo of the procedure, or having the parents watch a video, sometimes might increase understanding of the process and may prompt or clarify questions.
Specific Techniques

Restraint. No consensus exists among states for the definition of restraint or what constitutes the use of restraints. Each practitioner should clarify the issue with the State Board of Dentistry before establishing an office policy about restraints. The Academy of Dentistry for the Handicapped (now renamed the Academy of Dentistry for Persons with Disabilities) issued recommendations in 1987, some of which are summarized here:

- Restraint shall be employed only when absolutely necessary.
- When deemed necessary, the least restrictive alternative should be chosen.
- Restraint shall not be used as punishment.
- Restraint shall not be used solely for the convenience of the staff.

The use of restraints is recognized as acceptable dental practice when appropriately applied to control behavior while administering dental care to patients who are developmentally disabled.

More acceptable terms for restraint are “stabilization” or “immobilization” to help position the child and to prevent injury. Methods vary from assistance in holding the child’s hands or legs still, using positioning devices, a seatbelt or shoulder support in the dental chair or wheelchair, or using a commercial product such as a PediBoard™. Care is necessary to avoid bruising the skin, overheating in the wraps, or perceptions of punishment by the parents or the child.

Nitrous oxide is administered to reduce anxiety, reduce gagging, raise the pain-reaction threshold, and relax the child. Sometimes the nosepiece and the sensation have an opposite effect so that the child becomes frantic and extremely fearful. Many children with developmental disabilities are mouthbreathers, which may make nitrous oxide ineffective.

Oral or parenteral conscious sedation can also be used, but needs to be closely monitored and sometimes has an opposite effect, making the child hyperactive. Children with special health care needs may respond inconsistently to premedication. Standard dosage parameters of age and weight are not always applicable. IV sedation seems to be more reliable than oral sedation.

General anesthesia for dental care sometimes is necessary and can be done in an ambulatory care setting, a same-day surgery center, an outpatient surgery center, or an inpatient hospital setting. Some children have medical conditions (e.g., certain respiratory disorders or heart conditions) that may contraindicate use of general anesthesia for routine dental care. Conscious sedation, deep sedation and
general anesthesia should only be provided by qualified and appropriately trained and certified professionals in accordance with state regulations.

When using any behavioral management technique, include a narrative description in the child’s dental record as well as a consent form. Documentation should include the type of behavior management used, the indications for the decision to use the technique, how long it was used, monitoring procedures, the process for informed consent, and what instructions were given to the parents before and after the treatment.

Advanced management techniques are usually only appropriate when dental treatment is required and should not be used routinely for examinations or preventive procedures such as sealants or prophylaxes. Behavior management that is beyond the current educational training and clinical experience of the dental practitioner and office staff should prompt a referral to practitioners who can render care more appropriately and effectively.
Consent for the Use of a Papoose Board

It occasionally becomes necessary to control excessive head, arm and leg movements to provide safe, comfortable and quality dental treatment. These patients are usually very young, fearful and may be moderately disabled.

A technique that we use for stabilizing children’s arms, legs and body is the Papoose Board with cloth wraps.

By signing below, you state that you give permission to _________________________, (name of health professional) to use the Papoose Board today to care for your child. You acknowledge that the procedure and its risks and benefits have been explained to you, that you understand the information, your questions have been answered, and other treatment options have been offered.

Thank you for taking the time to read and sign this document.

PRINT PATIENT’S NAME ___________________________ YOUR SIGNATURE ___________________________

PATIENT’S AGE ___________________________ PRINT YOUR NAME ___________________________

WITNESS’ SIGNATURE ___________________________ YOUR RELATIONSHIP TO PATIENT ___________________________

PRINT WITNESS’ NAME ___________________________ TODAY’S DATE ___________________________

Adapted from “Consent for the use of a Papoose Board”, University of the Pacific School of Dentistry, San Francisco, California
# Dental Specialty Resources for Children with Special Health Care Needs

<table>
<thead>
<tr>
<th>Providers</th>
<th>Address</th>
<th>Phone</th>
<th>Accessibility</th>
<th>Limitations</th>
<th>Payment</th>
<th>Training</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric Dentistry</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Orthodontics</td>
<td></td>
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<tr>
<td>Oral Surgery</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Dental Specialty Resources for Children with Special Health Care Needs: Completion of Form

Providers: List name of clinic, group, etc. and names of all providers who see children with special needs.
Address: Address of offices; include second office if applicable.
Phone: Phone number for making appointments, direct phone to dentist if applicable, or after-hours number.
Accessibility: Accessibility could include codes such as — PTR: on public transportation route. PF: free parking,
PP: pay parking, WA: wheelchair accessible. EH: evening hours. SH: Saturday hours.
Languages: Spanish, Cambodian, Vietnamese, Russian, etc.
Limitations: Limitations could include comments such as— Children ages 4-16. No new patients until March.
3 month wait for appointment. 2 new Denti-Cal patients/month. Open bay — no private rooms.
3/4 of operators can’t accommodate wheelchairs.
Payment: Payment methods could include codes such as — DC: Denti-Cal. DD: Delta Dental.
CCS: California Children Services. OTP: Other Third Party. EPP: Extended Payment Plan.
FPAtV: Full Payment At Visit. CP: Co-pay Per Visit. HF: Healthy Families.
Training: Special course in serving children with special health care needs. Experience treating children with special health care needs during specialty training. ADPD (Academy of Dentistry for Persons with Disabilities)
membership. Hospital appointment or on cleft palate or oncology team.
Other: Other issues such as types of management techniques used (e.g., nitrous oxide, general anesthesia,
papoose boards), willing to do oral screenings in community settings, willing to give presentations to parents/caretakers or trainings for other healthcare providers.
Preparing Children and Their Families for the Hospital Dental Experience

The hospital dental experience can cause a great deal of fear and anxiety in a child. Such concerns may include:

- Separation from family and home
- Dental treatment/surgery
- Masked and gowned strangers
- Needles and medicine
- New sights, sounds, and smells.

To ensure that children and their families are informed, and are supported prior to, during, and following the hospital experience, it may be helpful to provide them with the following information in case the hospital does not.

**Before the Hospitalization:**

- What medications the child will be taking before the procedure and a review of what medications the child already is taking for any possible adjustments.
- What diet restrictions the child must follow.
- Where the procedure will take place.
- How the child will be transported.

**During the Procedure:**

- Who will perform the procedure.
- Whether the child will be awake, sedated, or anesthetized.
- How the child will be positioned (whether the child will be secured or required to remain still).
- How the child will be clothed.
- Whether the child will be attached to any equipment.
- What medications the child will receive and the route of administration.
- The approximate length of the procedure.
- The degree of discomfort (from all sources) that the child might expect.
- What the child is allowed to do for him/herself.
- Where the parents will be during the procedure.
After the Procedure:

- What degree of pain the child might be expected to experience.
- What medications the child will take.
- Where the child will be taken.
- What restrictions will be placed on the child and for how long.
- What the child’s appearance may be – discoloration of skin, swelling, an incision site, a bandage or packing, or intravenous medication apparatus.
- Home care procedures after discharge.

To help reassure a child prior to hospitalization, remind him/her that:

- People in the hospital are there to help when you need extra care.
- If an overnight stay is needed, sometimes your parents can stay overnight with you.
- You can bring your favorite things from home.
- If something hurts or you are scared, let a grown-up know.
- It’s okay to ask about things you don’t understand.
- Most hospitals have playrooms where you can play and meet friends.
- When you get home, you can make a book about your hospital stay or play hospital with your friends.
Indicators of Quality Dental Care

Section Overview
This section contains items that relate to quality dental care for children with special health care needs from the family’s perspective. They were developed specifically for the California Connections Project.

Indicators of Quality Dental Care for Children with Special Health Care Needs
Included is a checklist of indicators that relate to the family’s ability to access care and then receive quality dental care. They can be adapted for individual practices or integrated with other quality assurance measures used by managed care plans. Dental offices can use these indicators as a report card of how well you are providing services.

Family Satisfaction Questionnaire
The questionnaire may be used to obtain feedback from families on how satisfied they are with the care their child receives and with the dental team members who provided the care. It can be used for any family, not just those with children who have special health care needs.
Indicators Of Quality Dental Care for Children with Special Health Care Needs

Access to Care
- Family receives names of dentists/dental practices or a direct referral.
- Child is seen for a dental screening by age one or by the eruption of the first tooth, whichever comes first.
- Dental benefits and limitations of coverage are explained in the family’s primary language and at a level they can understand.
- Family does not experience denial of care due to child’s special health care needs.
- Family does not experience denial of care due to child’s special health care needs.
- Family is able to schedule an appointment for initial or routine care within 1 month of calling.
- Child is able to be seen for dental emergency by a dental provider within 24 hours.
- Specialty services are available and facilitated by a direct referral.
- Potential obstacles to care (such as transportation) are assessed and resources are identified to help alleviate the obstacles.

Quality of Care
- Family is informed about the oral health, oral development status, and dental needs of their child.
- Family is taught effective preventive oral care procedures to use with their child at home.
- Family is given anticipatory guidance to prevent future oral diseases or injuries.
- Family is involved in dental care decisions.
- Informed consent for treatment is given in family’s primary language at a level they can understand.
- Dental care is provided in the least restrictive and safest environment for the child.
- Family members and child are treated with dignity and respect by providers and staff.
- Child is able to receive care according to the identified needs.
- Treatment needs and preventive care are completed in a timely manner and a recall cycle is initiated of at least yearly care.
- Care among multiple providers is coordinated and there is interprofessional communication.
- Child’s oral health status improves as a result of care.
Family Satisfaction Questionnaire

We would like to know how satisfied you were with your child’s appointment today. Please answer the following questions to help us provide quality care to all of our patients. Your answer will be confidential — you do not need to sign your name.

1. What did you expect for your child’s appointment today and what was actually done?

<table>
<thead>
<tr>
<th>Expected</th>
<th>Received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>An exam</td>
<td>No Yes</td>
</tr>
<tr>
<td>X rays</td>
<td>No Yes</td>
</tr>
<tr>
<td>Teeth cleaning</td>
<td>No Yes</td>
</tr>
<tr>
<td>Other preventive procedures</td>
<td>No Yes</td>
</tr>
<tr>
<td>Dental fillings</td>
<td>No Yes</td>
</tr>
<tr>
<td>Extractions</td>
<td>No Yes</td>
</tr>
<tr>
<td>Counseling about home oral care</td>
<td>No Yes</td>
</tr>
<tr>
<td>Referral to a specialist</td>
<td>No Yes</td>
</tr>
<tr>
<td>Don’t know</td>
<td>No Yes</td>
</tr>
<tr>
<td>Other______________________________________</td>
<td></td>
</tr>
</tbody>
</table>

Comments:

2. How satisfied were you with each of the following?

<table>
<thead>
<tr>
<th></th>
<th>Very Dissatisfied</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling appointment at convenient time for us</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time between making appointment and being seen</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time waiting in reception or exam room</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent with our child during appointment</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time spent discussing care with us</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explanation of office policies and procedures</td>
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<td></td>
</tr>
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<td>Payment policies and arrangements</td>
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<tr>
<td>Explanation of exam or dental procedures</td>
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</tr>
<tr>
<td>Interactions with front office staff</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:

3. How would you rate the dental health professionals who provided care for your child?

<table>
<thead>
<tr>
<th></th>
<th>Poor</th>
<th>Ok</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made us feel welcome</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encouraged us to ask questions</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listened to our opinions and concerns</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asked enough health and social history questions to understand our child’s abilities and needs</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explained things clearly</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Showed a caring attitude toward our child</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gave us information to take home</td>
<td>No Yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Obtained consent for special behavior management techniques and dental care which we understood
Emphasized the importance of prevention
Involved us in making dental care decisions
Used up-to-date techniques
Respected our values and beliefs
Discussed need for follow-up and recall appointments
Spoke our language or arranged for language interpretation

Comments:

4. Put a check in the box if you encountered any of the following obstacles when seeking care at our office. If you did, please describe the obstacles so we can consider improvements.

- Physical obstacles in parking lot, entering building, or inside the office
- Communication barriers
- Transportation problems
- Need to take time off from work
- Need to arrange child care for other children
- Other__________________________

5. What could we have done to make your visit more comfortable?
Section Overview
This section contains materials that pertain to some of the community programs and/or services that may be helpful to dental team members who provide care to families of children with special health care needs. Note that resources and contact numbers may change over time.

Overview of Community Resources and How They Can Help with Dental Care
Some of the programs and services are described that may be available in the community to assist providers and families in locating additional support, services or information.

California Children Services (CCS)
A list of State, Regional and County CCS offices, with the addresses/telephone numbers.

California Family Resource Centers/Networks
A list of all the Family Resource Centers/Networks in California, with the addresses/telephone numbers.

California Regional Centers
A list of the 21 Regional Centers that are under the administration of the California Department of Developmental Services.
Overview of Community Resources and How They Can Help with Dental Care

Denti-Cal Program
Children with special needs who are Medi-Cal eligible may receive dental care from a provider who is participating in the state and federally funded Denti-Cal program. The Denti-Cal program is administered by the California Department of Health Services and serves low-income individuals who would otherwise not have access to dental care. A primary care physician may refer a child to a dentist but ordinarily families seek a Denti-Cal dentist on their own. Denti-Cal participating dentists are reimbursed directly by the Denti-Cal program. For more information, providers may contact: (800) 423-0507. Beneficiaries may call: (800) 322-6384.

California Children Services (CCS)
Administered by the California Department of Health Services, CCS serves children under the age of 21 with certain genetic, neurologic and orthopedic conditions. Services are arranged for and provided to these children through county and State regional offices. Family eligibility is determined by the child’s medical condition, adjusted gross income, and residency requirements. Children who are not Medi-Cal eligible but who are eligible for CCS may receive dental services (including preventive and restorative services, and general anesthesia when administered in a CCS-approved facility) that are paid for by CCS under certain conditions, e.g., when a child has disabling malocclusion, cleft palate or craniofacial anomalies, when routine dental care is complicated by the CCS-eligible condition or when specialized dental care is part of the treatment plan for the CCS-eligible condition. For more information, contact your local health department or (916) 654-0499.

Dental Schools
Five dental schools are located in California — two in Northern California in San Francisco (University of California, San Francisco (415) 476-1891 and University of the Pacific (415) 929-6501), two in Southern California in Los Angeles (University of California, Los Angeles (310) 206-3904 and University of Southern California (213) 740-0412) and one in Loma Linda (Loma Linda University (909) 824-4222). Most do not have separate clinics for children with special needs but integrate these children into the general pediatric
or advanced general dentistry clinics. Financing of dental care in most dental schools is through third-party payors, including Denti-Cal, or fee-for-service (usually reduced fees).

**Donated Dental Services (DDS)**
The DDS program is funded through the Foundation of Dentistry for the Handicapped, a charitable affiliate of the American Dental Association. The program serves people of all ages, who because of serious disability, advanced age, or medical problems, lack adequate income to pay for needed dental care. There are no rigid financial eligibility requirements. Individuals who qualify are generally treated at no cost; however, those who can pay for part of their care may be encouraged to do so, especially when laboratory work is involved. Anyone may submit an application that will be reviewed by a referral coordinator who may call to obtain additional information. Applicants are matched with a volunteer dentist who sees the patient and schedules the work. For an appointment and more information, contact the Northern California DDS Coordinator at (916) 498-6176 or the Southern California Coordinator at (310) 258-4006.

**Regional Centers**
The regional center system for individuals with developmental disabilities in California, which includes 21 regional centers, was established by the Lanterman Mental Retardation Services Act of 1969. Each regional center is a private nonprofit corporation working under contract with the California Department of Developmental Services. Any California resident with a known developmental disability attributable to mental retardation, cerebral palsy, epilepsy, autism, or other handicapping conditions found to be closely related to mental retardation, is eligible to receive services. The disability must begin before the 18th birthday, be expected to continue indefinitely, and present a substantial disability. Infants and children (birth through 3 years old) are eligible for services if they have one of the covered conditions or are at risk for a developmental disability. A variety of services may be purchased depending upon the needs of the consumer and available funding. If dental problems are detected by the client service coordinator, dental services may be arranged and paid for by the regional center. To locate a regional center in your area, see the attached list or contact the Regional Center Branch at the California Department of Developmental Services at (916) 654-1954.
Family Resource Centers/Networks
For children with special health care needs, parent-to-parent support is provided by a varied group of nonprofit, often times parent-run organizations. These include: federally-funded parent training and information (PTI) centers (US Department of Education); disability specific groups such as the Learning Disabilities Association, United Cerebral Palsy, the Area Resource Councils, Children and Adults with Attention Deficit Disorder, the Autism Society; and the statewide network of Family Resource Centers/Networks. The centers are funded to provide support, training, and information to families with children with special needs (Early Start Program). Frequently, other parents are the best source for finding specialty dental care.

Local Dental Societies and Dental Hygiene Components
For information about dental referral resources in your community, local dental societies and dental hygiene components may be helpful. Call the California Dental Association for the telephone number of the dental society in your area (800) 736-8702 or the California Dental Hygienists’ Association for the telephone number of your local dental hygiene component (916) 442-4331.
Section Overview
This section contains a variety of resources and references for dental teams. They represent informal and formal opportunities to increase your knowledge and skills in providing special patient care as well as resources for referral or specialized equipment. This is not a complete list but focuses on selected resources and references relevant to the information in the planning guide.

Resources
Selected books, newsletters, training and continuing education programs, clearinghouses and sources for dental references and special equipment are included. Note that contact information for organizations may change over time.

Bibliography
Selected references are included to document sources of information used in developing this guide as well as an array of articles for further reading on various topics.
Resources

Books
- Contact: National Maternal and Child Health Clearinghouse
  2070 Chain Bridge Road, Suite 450
  Vienna, VA 22182-2536
  Phone: 703-356-1964
  Fax: 703-821-2098
  www.brightfutures.org

Newsletters
- Contact: Librarian
  National Center for Education in Maternal and Child Health
  2000 15th Street, North, Suite 701
  Arlington, VA 22201-2617
  Phone: 703-524-7802
  Fax: 703-524-9335

- Contact: Head Start Publication Management Center
  USDHHS
  Washington, DC 20201
  Fax: 703-683-5769

- Contact: Department of Developmental Services
  1600 9th Street
  Sacramento, CA 95814
  Phone: 916-654-1722
  Fax: 916-654-3020
  www.dds.caahwnet.gov

Interface (Newsletter) and Special Care in Dentistry (Journal).
- Contact: Academy of Dentistry for Persons with Disabilities
  211 E. Chicago Ave.
  Chicago, IL 60611
  Phone: 312-440-2660

Dental Care Planning Guide February, 2000
USC University Affiliated Program Children's Hospital Los Angeles
Training and Continuing Education Programs

DECOD, Dental Education in Care of the Disabled — A training program that provides self-instructional manuals for CDE credits as well as short- or long-term clinical courses. Some stipends available.

Contact: DECOD Program
    School of Dentistry, Box 357137
    University of Washington
    Seattle, WA 98195
    Phone: 206-543-5448
    Fax: 206-685-3164

Overcoming Obstacles to Dental Health — A training program (video, workbook, and trainer's manual) for using with caregivers of people with disabilities.

Contact: Paul Glassman or Christine Miller
    The University of the Pacific School of Dentistry
    Department of Dental Practice
    2155 Webster St
    San Francisco, CA 94115
    Phone: 415-929-6428
    Fax: 415-929-6654

Southern Association for Institutional Dentists — Self-study courses and guidelines for dental professionals and institutions serving people with mental and physical disabilities.

Contact: c/o Donna Spears, DDS, MPH
    PO Box 258
    Butner, NC 27509-0258

Clearinghouses

Publications, on-line oral health database, resource links.

Contact: National Oral Health Information Clearinghouse
    1 NOHIC Way
    Bethesda, MD 20892-3500
    Phone: 301-402-7364
    TTY: 301-656-7581
    Fax: 301-907-8830
    ww.aerie.com/nohicweb
Dental Referrals or Information
Contact: California Society of Pediatric Dentistry — Publications and directory of pediatric dentistry members by area.
Phone: 310-548-0134
www.cspd.org

Contact: Federation of Special Care Organizations and Academy of Dentistry for Persons with Disabilities (in cooperation with Special Olympics/Special Smiles)
211 E Chicago Ave
Chicago, IL 60611
Phone: 312-440-2660
www.bgsmedu/dentistry/foscod
www.specialsmiles.org

Specialized Equipment and Oral Hygiene Aids
Rainbow Pedi-Board™ Stabilizing System, Open-Wide® disposable mouth props.
Contact: Specialized Care Company
206 Woodland Road
Hampton, NH 03842
Phone: 800-722-7375
Fax: 603-926-5906
Stabilizers, physical safety holders.
Contact: T Posey Company
5635 Peck Road
Arcadia, CA 91006
Phone: 800-447-6739
Bite blocks, lip/cheek retractors.
Contact: McKessen/MDT Biologic
19645 Ranch Way
Rancho Dominguez, CA 90220
Phone: 800-347-4038
Collis Curve Toothbrush. Three-sided brush, outer two rows are curved inward with a single short straight row down the center. Youth size (not for crowded or crooked teeth)
  Contact: Collis Curve Toothbrush Catalog
  302 N Central Avenue
  Brownsville, TX 78521
  Fax: 210-546-4818

DexTBrush. Designed for individuals with limited gripping ability.
  Contact: Preventive Dental Services, Inc.
  903 Grand Avenue
  Rothschild, WI 54474
  Phone: 800-352-9669

Nuk Massage Brush. May be used to help desensitize orally defensive children.
  Contact: Gerber Products Company
  PO Box 120
  Reedsburg, WI 53959-0120
  Phone: 800-443-7237 or
  608-524-9380 ext. 380
Bibliography

- ADH. Ad Hoc Committee Report. The Use of Restraints in the Delivery of Dental Care for the Handicapped: Legal, Ethical, and Medical Considerations. March 1987.


- Shauman SK and Bebeau MJ. Ethical and legal issues in special patient care.
- Tesini DA and Fenton SJ. Oral health needs of persons with physical and mental disabilities.


