Providing Family-Centered Care in Dentistry

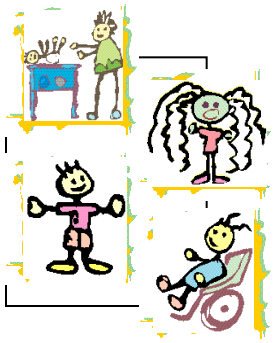
Families who have children with special health care needs are faced with many challenges in today's healthcare systems. Dental care is an important piece of that system. Frequently, multiple agencies and providers are involved in the care of a child, making coordination of services important. Family-centered 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.

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.

Dental Office Considerations Checklist

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 operatory 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.

Oral Assessment and Prevention

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.

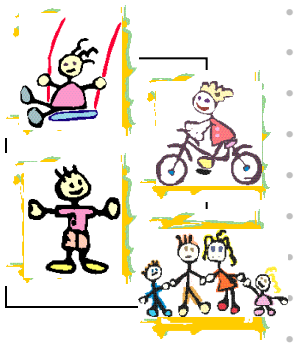
Dental Health Education Materials

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.

Performing the Oral Assessment for Young Children with Special Health Care Needs



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:

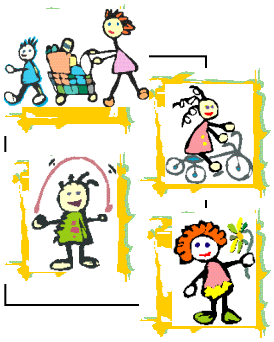
- ▲ Prenatal, natal and neonatal history: this might be helpful in explaining any dental abnormalities or immature motor reflexes.
- ▲ Developmental history: a brief overview of the parents' perceptions of the child's development helps correlate dental growth and development with general developmental 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".

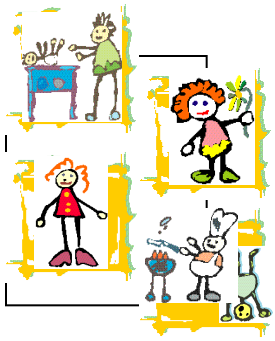
Dental Caries

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.

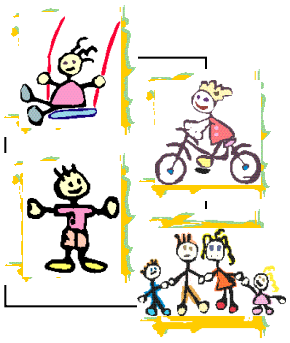


Moving intraorally, check for malocclusion in the primary teeth tha may create problems in the permanent dentition. Malocclusions occur frequently in children with developmental problems (more than 80 craniofacial syndromes exist). Hypoplasia of the maxilla, micrognathia, and prognathia are especially prevalent.

Delayed eruption of teeth is seen in children with certain genetic disorders, particularly Down syndrome, or in children with genera 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 du 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 o 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 conrol 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.

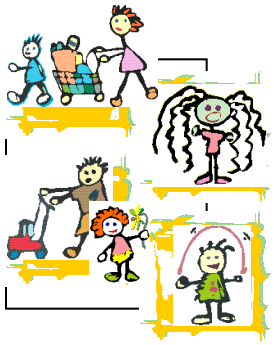
Home Care Counseling and Anticipatory Guidance for Oral Health

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 growtl 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.



Information adapted from the publication: Casamassimo P. *Bright Futures in Practice: Oral Health.* Arlington, VA, National Center for Education in Maternal and Child Health, 1997.

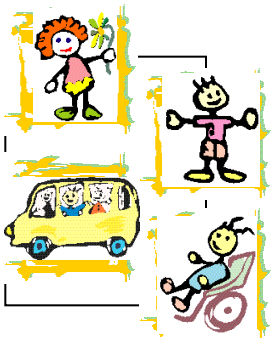
Anticipatory Guidance

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.



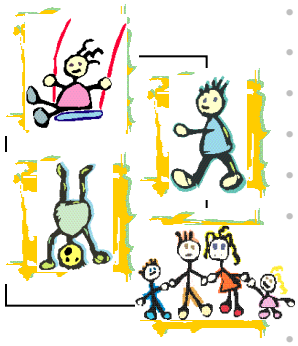
Discuss the benefits of dental sealants in preventing tooth decay.

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).



Dental Health Education Materials

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.

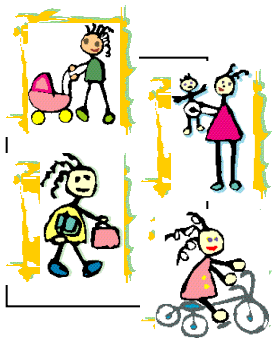
Selected Brochures, Pamphlets

Selected resources for parents are included because they are specifi 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://cudental.creighton.edu/asdc

In-Office Preventive Dental Procedures



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.