



**Proceedings**

**Promoting Oral Health  
Of Children with  
Neurodevelopmental Disabilities  
And Other Special Health Needs**

**A Meeting to Develop Training and Research Agendas**

**May 4-5, 2001**

**Center on Human Development and Disability  
University of Washington, Seattle**

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# Acknowledgments

This volume contains the proceedings of a conference held at the Center on Human Development and Disability, University of Washington Center, on May 4-5 in Seattle. The Pacific West Consortium of Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs, in collaboration with the University of Washington Comprehensive Center for Oral Health Research, convened health care professionals, educators, policy makers, researchers, and parents to develop training and research agendas related to oral health promotion for children with neurodevelopmental disabilities and other special health care needs.

The conference was co-sponsored by the Health Resources and Services Administration's Maternal and Child Health Bureau, in collaboration with other public and private partners. The meeting was held in conjunction with a Rome Community Access to Child Health (CATCH)<sup>1</sup> Visiting Professorship in Community Pediatrics, sponsored by the American Academy of Pediatrics and the American Academy of Pediatric Dentistry Foundation, which made possible the participation of Dr. Harold Slavkin.

The Pacific West LEND Consortium consists of four centers: the Center on Human Development and Disability, University of Washington; the Center for Disabilities Studies, University of Hawaii; the Oregon Institute on Disability and Development, Oregon Health and Science University; and the Center for Child Development and Developmental Disabilities, University of Southern California, Childrens Hospital, Los Angeles.

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## Proceedings

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<sup>1</sup> The CATCH program was established in honor of pediatrician-advocate Leonard P. Rome, MD.

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## Executive Summary

In follow-up to *Oral Health in America: A Report of the Surgeon General and The Face of a Child: Surgeon General's Conference on Children and Oral Health*, this conference was convened to address training and research agendas related to oral health promotion for children with neurodevelopmental disabilities and other special health care needs. Key conference themes and recommendations include the following.

**Children with neurodevelopmental disabilities and other special health care needs are at increased risk for oral problems.** These include: 1) common oral diseases such as caries and periodontal disease; 2) serious health consequences from common oral disease due to underlying medical conditions; 3) oral consequences of medical therapies; and 4) less common oral and craniofacial problems that also affect their overall health, quality of life, and long-term outcomes. Children with neurodevelopmental conditions may be at special risk for oral disease due to delays in acquiring self-care skills, knowledge, and understanding needed to promote oral health.

**These children face many barriers to needed oral health care.** Dental care is the number one unmet health care need of children with special health care needs. Children with neurodevelopmental disabilities and other special health care needs face barriers to care for many reasons, including critical dental provider workforce shortages and geographical maldistribution of providers, a lack of dental professionals trained in the care of children and special populations, and a lack of medical and other health practitioners trained in oral health promotion. In addition, many of these children lack oral health coverage, especially for complex oral and craniofacial care. Moreover, dental and medical systems operate separately, undermining the broader vision of interdisciplinary, integrated services for these children. Finally, systems of care do not always work collaboratively with parents and social service and educational systems serving children and families. A comprehensive *child-specific definition of medical necessity* takes into account developmental, health, social, cultural, family, and environmental factors affecting children, and it includes oral health and preventive therapies as part of overall health care. Such health coverage is needed for all children, including those with special health needs.

**There are critical gaps in the evidence base** needed to promote the oral health of these children and in the application of new science and technologies to their care. There is insufficient attention to important

*With improved survival of individuals with neurodevelopmental disabilities and other special health care needs, oral disease prevention must be a priority.*

related areas such as nutrition, speech, oral-motor function, quality of life, oral-systemic health interactions, and development of health-promoting behaviors. Analysis of existing research is complicated by use of different diagnostic criteria for study populations.

**Interventions must emphasize prevention and health promotion.**

Despite data gaps, there is good reason to believe that most oral disease could be prevented in these children. Current understanding of disability and health promotion dictates that actions extend beyond individual and professional interventions and address societal determinants of health. This is particularly important for individuals with neurodevelopmental disabilities, who are disadvantaged in a system that relies heavily on personal skills and access to professional care that may be limited. With improved survival of individuals with neurodevelopmental disabilities and other special health care needs, oral disease prevention must be a priority.

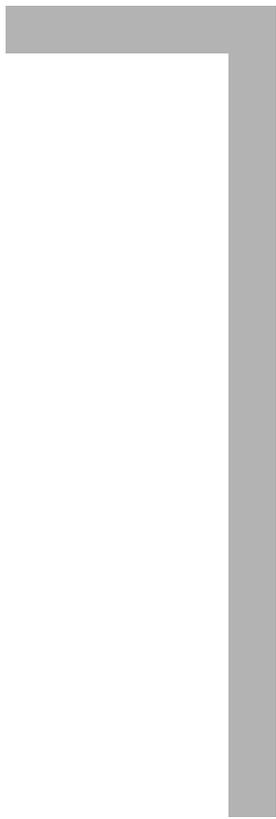
**Interdisciplinary efforts can help promote oral health of children with special needs.**

These challenges call for changes in professional training, research in special populations, integration of health services, and policy strategies to promote oral health. Collaboration with families, health care providers inside and outside of dentistry, professional societies, policy makers and other partners is needed to accomplish these changes. Existing resources and opportunities include the interdisciplinary training and research centers in mental retardation and developmental disabilities, model programs such as Special Olympics, Special Smiles, and concurrent state, regional, and national activities. Given their unique focus and scope of activities, the Health Resources and Service Administration's Maternal and Child Health Bureau-funded centers for leadership education in neurodevelopmental and related disabilities (LEND) and pediatric dentistry should take leadership roles in seeding needed changes in training, research, services, and policy for these children.

## **Highlights of Recommendations**

### **I. Provide optimal education and training for families, health professionals, and the public.**

1. Educate families and all health professionals in oral health promotion and disease prevention and oral-systemic health interactions for children with neurodevelopmental disabilities and other special health care needs.
2. Educate dental professionals in maintaining a broad view of child health, including developmental, family, social, cultural, and environmental determinants of health.

- 
3. Educate health professionals and families in oral health promotion through community and system level actions, advocacy, and policy change.
  4. Increase opportunities for interdisciplinary collaboration between health professionals including dental, medical, nursing, nutrition, pharmacy, public health, and others.
  5. Use leadership training programs in neurodevelopmental disabilities (LEND), pediatric dentistry and others to promote critical changes in education, training, research, service, policy for children with neurodevelopmental disabilities, and other special health care needs.
  6. Garner support of professional organizations and certifying and licensing bodies for needed educational and training changes.
  7. Expand awareness of the importance of oral health among policy makers, program administrators, and the public with consistent messages and targeted communication.
  8. Evaluate effectiveness of educational programs for families, professionals, and the public

## **II. Foster research and translation of science.**

1. Expand research agendas in oral health for children with special health care needs, including epidemiological, health services, clinical, behavioral, and oral-systemic health linkages.
2. Enhance translation of science of caries prevention and other discoveries to care for children with special health care needs.
3. Consider national consensus conferences in critical areas: nutrition and oral health; health promotion; quality of life; and oral health promotion in special populations.
4. Support behavioral and education research on the best ways to accomplish training objectives for professionals and families.

## **III. Create integrated service models and demonstration projects.**

1. Ensure children with special health care needs have dental homes, medical homes, and needed interdisciplinary care that integrates oral and general health.
2. Individualize treatment for each child and family, including oral health perspective.
3. Include oral health evaluations as part of comprehensive EPSDT exams and develop guidelines for such assessments.
4. Ensure presence of integrated dental and oral health services at children's hospitals and tertiary care centers.

5. Reach out to children and families across other systems, especially in neurodevelopmental centers; use interdisciplinary providers and allied dental professionals such as dental hygienists to integrate oral health care in diverse settings.
6. Ensure outreach, case management, and other enabling services for children with special health care needs to ensure children receive needed oral health care.
7. Ensure cultural competency of systems and providers relating to children and families with special needs.
8. Develop demonstration projects in oral care of children with special needs.
9. Ensure transition of adolescents with special health needs to adult health care services.

#### **IV. Support critical policy change and standards of care.**

1. Ensure health insurance coverage for all children including those with special health needs.
2. Develop child-specific definitions of medical necessity that include oral health care and hold health systems accountable to standards.
3. Develop incentives that encourage dental professionals to work with children with special health care needs.
4. Develop a comprehensive oral health promotion policy agenda.
5. Consider policies that facilitate adolescent transition to adult health care services.

#### **V. Use partnerships to address oral health disparities in children with special health needs.**

1. Ensure participation of families to promote oral health training, service, and research and policy agendas for these populations of children. Include culturally diverse perspectives.

The complete Conference Agenda and Proceedings will also be available at <http://depts.washington.edu/ccohr>

## Introduction and Overview

Wendy E. Mouradian, MD, MS

### Conference goals

The primary goal of this conference was to develop training agendas for health professionals and families related to oral health promotion for children with neurodevelopmental disabilities and other special health care needs. A secondary goal was to consider oral health research, service, and policy needs for these populations. These goals were addressed within the conceptual framework of this conference—defined as the intersection of *oral health, health promotion, and disability, in the target populations of children and families.*

This conference was viewed by organizers as a follow-up activity to *Oral Health in America: A Report of the Surgeon General*<sup>1</sup> and *The Face of a Child: Surgeon General's Conference on Children and Oral Health*.<sup>2</sup> Both the report and conference called for increased attention to populations with special health care needs and disabilities and for enhanced oral health education for health professionals, patients, policy makers, and the public.

### Background

*Disparities in oral health of children with neurodevelopmental disabilities and other special health care needs.*<sup>3</sup> Although it is known that profound disparities exist in the oral health of children from low-income and minority families,<sup>4,5</sup> no national database exists to document oral health status of children with neurodevelopmental disabilities or other special needs.<sup>6</sup> Clinical accounts and emerging data attest, however, to increased risks of oral disease in children with special health care needs,<sup>7,8</sup> and individuals with neurodevelopmental disabilities in particular,<sup>9,6</sup> as discussed by Wagner (below). Children with neurodevelopmental disabilities may be particularly vulnerable to oral disease due to delays in cognitive, motor, sensory, communication, or social-adaptive abilities that affect understanding and acquisition of self-care skills.

*Gaps in access to oral health care.* Dental care is the most prevalent unmet health need among all children<sup>10</sup> and among children with special health care needs.<sup>11</sup> In a survey of state directors of Title V programs for children with special health care needs that assessed provider capacity for this population, access to dental care received the lowest scores, with no state reporting adequate access for this population.<sup>12</sup> A recent survey of academic pediatric dental departments, which serve as safety

*A recent national oral health survey of pediatricians demonstrates a lack of training and knowledge in oral health but recognition of its importance.*

nets for children with special health care needs, revealed many are overburdened, with waits of up to seven months for operating room time.<sup>13</sup> Barriers cited by Title V directors included lack of dentists with pediatric expertise in managed care networks, shortage of and geographical maldistribution of dentists, linguistic and cultural barriers, inadequate reimbursement, and restrictive interpretations of “medical necessity.”

Inadequate access to pediatric dental care under Medicaid has been previously documented: fewer than one in five Medicaid-eligible children received preventive dental care in 1993.<sup>14</sup> This situation could have a greater impact on children with special needs, because a disproportionate number of them are covered by Medicaid or other form of public insurance.<sup>10,11</sup> In addition, the consequences of lack of care may be more profound because these children’s oral needs are greater than average. Poor and near-poor families of children with developmental disabilities are more likely to report unmet dental needs due to cost barriers than similar families of children without disabilities.<sup>15</sup> The impact of new State Child Health Insurance Program (SCHIP) plans<sup>16</sup> on access to dental care for children with special health care needs has not been adequately evaluated.

Chronic access problems for individuals with developmental disabilities in both community and institutional settings are explored in papers by McIver, Kanellis, and Cheffetz below. They identify barriers at system, provider, family, and individual and child levels.

*Gaps in training.* The shortage of dental providers available to treat these children is discussed by Nowak and Casamassimo. Historically, the burden of care for these children has fallen on a disproportionately small group of dentists, primarily pediatric dentists. General dental undergraduate curricula are lacking in this area.<sup>17</sup> At the same time, training of medical professionals in children’s oral health promotion has lagged. A recent national oral health survey of pediatricians demonstrates a lack of training and knowledge in oral health, but recognition of its importance.<sup>18</sup> In the area of knowledge of craniofacial conditions, both medical and dental providers have demonstrated knowledge gaps.<sup>19,20</sup>

*Gaps in research.* There is also a lack of evidence to support the efficacy of many clinical interventions in special populations, Nowak and Casamassimo conclude from a review of the literature. There are almost no baseline data on caries experience, prevalence of untreated caries, or sealant usage in children and adolescents with disabilities, which are required for attaining key Healthy People 2010 oral health objectives (see especially Objectives 21-1, -2, -8, -10, and -12).<sup>21,22</sup> The prevalence

of various oral conditions in specific sub-groups of children with special health care needs must be better defined to confirm clinical reports.<sup>7,9</sup>

There are research gaps in health services and oral-systemic health linkages for special populations. The resources devoted to the study of oral health of special populations have not been adequate. Specific health promotion and other research gaps are noted by Crall and Braveman.

*Gaps in financing of services and policy.* Low reimbursement rates for children insured by Medicaid, a lack of coverage for general anesthesia, and the complex and time-consuming nature of oral health care for children with special needs all contribute to access problems. For pediatric dentists, most of whom already see children with special needs, the financial gap between private practice and academic or hospital employment limits the number specializing in this type of care. These factors have a critical impact on pediatric dental service, training, and research capacity in academic settings. Furthermore, pediatric dentists often follow these children into adulthood, further limiting their availability to accept new children with special needs.

The most obvious policy gap is the lack of affordable health coverage for all children. Lack of health insurance is the single largest risk factor for unmet dental needs.<sup>10</sup> Moreover, most health and dental insurance plans do not provide adequate coverage for specific oral therapies needed by children with neurodevelopmental disabilities and other special health care needs that might include oral-facial surgeries, orthodontics, dental implants and prosthetics, oral appliances, special nutritional interventions, and oral-motor therapies including speech therapy. Another gap is the failure to ensure that all Medicaid-eligible children, especially those with special health care needs, access the preventive and therapeutic dental care to which they are entitled. Finally, more widespread modification of current policy is needed to support expanded use of allied dental and primary care medical practitioners to deliver needed oral health promotion interventions in vulnerable populations, as is now possible in some states.<sup>23,24,25</sup> Policy changes could include reimbursement for oral services by these practitioners and relaxation of state dental practice laws.

*The most obvious policy gap is the lack of affordable health coverage for all children. Most health and dental plans do not provide adequate coverage for oral therapies required by children with special needs.*

### **Interdisciplinary training opportunities**

Concurrent with these startling needs are important opportunities for integration of oral health into interdisciplinary health professional training and research centers. Since 2000, the federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, has required competitive applications for Leadership Education

*Prevention of childhood caries, which is caused by an infection passed from mother to infant, requires interventions in infancy and early childhood.*

in Neurodevelopmental and Related Disabilities (LEND) program funding to include pediatric dentistry as a core discipline along with pediatrics, nutrition, occupational and physical therapy, speech and language, and others.<sup>26</sup> In addition, MCHB funds two centers for Leadership Training in Pediatric Dentistry and has called for applications for additional centers.<sup>27</sup>

Two other interdisciplinary programs that can integrate oral health into training, research, service, and policy for special populations are the University Centers for Excellence in Developmental Disabilities Education, Research and Service (formerly University Affiliated Programs), funded by the Administration on Developmental Disabilities, Agency for Children, Youth and Families; and the Mental Retardation Research Centers, funded by the National Institute of Child Health and Human Development, National Institutes of Health.<sup>28</sup>

### **Conceptual framework: intersection of four areas**

#### **1. What is oral health? <sup>29</sup>**

*Oral health is more than teeth.* Oral health includes all the sensory, digestive, respiratory, structural, and emotional functions of teeth, oral cavity, and contiguous structures—collectively known as the craniofacial complex.<sup>1</sup> The mouth is involved in systemic defense, and it often mirrors systemic problems such as immunologic disorders, infectious diseases, and nutritional deficiencies. Proper function of the craniofacial complex is essential for optimal nutrition, pulmonary health, speech production, communication, self-image, social function, and well-being. Oral health is essential to overall health, and common oral diseases affect overall health.<sup>30</sup>

As an example of the effects of oral disease on overall health outcomes, Quinonez discusses the association of maternal periodontal disease with risk of low birthweight babies and prematurity. Low birthweight increases an infant's risk of a neurodevelopmental disorder. If the research continues to be confirmatory, oral health interventions may provide an important opportunity for primary prevention of neurodevelopmental disabilities associated with low birthweight and prematurity.

*Basic concepts of oral disease.* The two most common conditions, dental caries and periodontal disease, are summarized briefly by Berg. Prevention of childhood caries, which is caused by an infection passed from mother to infant, requires interventions in infancy and early childhood.

Many children with special needs experience a heightened risk of oral disease. For example, children with Down syndrome, diabetes mellitus,

or on anticonvulsant therapies have a higher risk of periodontal disease. Children with gastroesophageal reflux, a history of prematurity, or on saliva-suppressing medications are at increased risk for caries. Or, as Williams discusses, untreated oral disease can cause life-threatening complications for children with cardiac anomalies or cancers or undergoing chemotherapy, immune suppressive treatment, or organ transplantation.

Other aspects of oral and craniofacial health critical for children with special health care needs include nutrition, oral-motor function, and speech (covered by Faine, Blasco and Trost-Cardamone, respectively). Children with congenital craniofacial conditions such as cleft-lip/palate, burns, and other craniofacial trauma highlight the vital role the orofacial complex plays in communicating ideas and feeling, and mediating some of our most human experiences. Daily social interactions and quality of life for these children can be affected by societal and cultural attitudes toward individuals with facial differences.<sup>31</sup> Children with special needs may be more vulnerable to both unintentional and child abuse injuries, many of which occur in oral and craniofacial areas.<sup>32,33</sup> Some children with special health care needs may have no “special” oral health needs, but should receive such preventive oral health care as part of complete health care.

*Oral health in America: gaps between science, practice, and policy.* The Surgeon General’s report on oral health highlighted the importance of oral health to overall health and well-being, the profound and consequential disparities in oral health status and access to dental care in some vulnerable populations, and the preventable nature of many oral diseases and conditions. Specifically, there is a failure to translate the science of caries prevention and disease management into practice<sup>1</sup> and under-utilization of preventive interventions, including community water fluoridation (less than two-thirds of community water supplies are fluoridated),<sup>34</sup> other fluorides, and dental sealants (less than a fourth of children have dental sealants).<sup>35</sup> A critical underlying problem is the lack of awareness of the importance of oral health among policy makers, other health professionals, and the public.

*Scientific frontiers, social and workforce trends.* Ironically, this state of affairs coexists with new genetic and scientific advances that link oral and systemic health and provide unprecedented opportunities for prevention and treatment of oral and craniofacial diseases. The oral health field is increasingly partaking of the scientific and technological revolutions (and their ethical, legal, and social dimensions) that are rocking health care, and that will change the face of dental care as we know it today.<sup>36</sup> Demographic trends influencing oral health care include a growing population of elderly, the increasing survival of individuals

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with chronic conditions requiring medical and oral health care, and an increasingly diverse population. The rising costs of health care, managed care, and an emphasis upon evidence-based approaches are also affecting dentistry. Finally, critical dental workforce issues include a declining pool of dentists, a very small number of pediatric dentists nationwide, a lack of qualified academicians and research scientists in the pipeline across oral health areas, and a lack of diversity among dental professionals. Concurrent with this is an underutilization of dental hygienists and other health professionals—including physicians—to promote oral health.

## **2. What is health promotion?**

*Health is not just the absence of disease.* As articulated by the World Health Organization (WHO), health is “a complete state of physical, mental, and social well-being, and not just the absence of infirmity”; “a positive concept emphasizing social and personal resources, as well as physical health.”<sup>37,38</sup> Nojack-Raymer discusses definitions of health and health promotion and how professionals can respond to the challenges of promoting individual and population health.

*Health promotion actions.* In the Ottawa Charter, WHO defined health promotion as “a process that enables people to increase control over the determinants of health and thereby improve their health” and suggested five Health Promotion Action Principles:<sup>39</sup>

1. Development of personal skills
2. Strengthening of community action
3. Creation of supportive environments
4. Building of healthy public policy
5. Reorienting of health services

The advantages of prevention early in life argue for a special emphasis upon health promotion actions targeted at children. Given their developmental immaturity and dependence on others, children require system-level actions in addition to skills-training for maximum health promotion. This is especially true for children (and adults) with neurodevelopmental disabilities, who experience a heightened vulnerability in personal skills, prolonged dependency, and problems accessing professional care. Moreover, individuals with certain neurodevelopmental disabilities, such as mental retardation, are now expected to live close to a normal life span,<sup>40</sup> underscoring the need for early preventive efforts.

These action principles also suggest that to improve health outcomes for individuals and populations, health professionals will need to take on

policy, advocacy, and administrative roles in order to affect system-level issues. All health professionals need to start thinking in new trans-disciplinary ways. Such approaches necessarily expand the scope of the traditional dental team to more collaborative, less hierarchical models.<sup>41</sup>

*“Common risk factor” approach.* Many risk factors for oral disease are risk factors for other health problems, suggesting that collaborative efforts might be a cost-efficient means to accomplish multiple health promotion goals simultaneously.<sup>42</sup> For example, many individuals with neurodevelopmental disabilities are at increased risk for obesity and diabetes.<sup>43,44,45</sup> Poor nutritional habits increase the risk of caries and obesity; obesity increases the risk of diabetes; diabetes independently increases the risk of periodontal disease.<sup>1 p 113-5</sup> Targeted nutrition interventions could diminish risks of several adverse, interrelated health outcomes at the same time. Similarly, prevalence of smoking in some groups of individuals with mental retardation is similar to that of the general public.<sup>46</sup> Smoking increases the risk of periodontal disease, caries, and oral cancer, as well as heart and lung disease.<sup>1 p 48; 203t, 106</sup> A common risk factor approach here would advocate combined smoking cessation and oral interventions to simultaneously decrease risks of oral, cardiovascular, and pulmonary diseases. Finally, stressed families may be at risk for child abuse and neglect, low utilization of health services, and increased oral and systemic disease rates, making it important to add oral health components to social and health interventions targeted at these families. These kinds of solutions again underscore the need to provide dental professionals with a broad context for understanding the needs of children and families and the communication skills necessary to work on inter-professional health teams.

*Quality of life.* Quality of life (QOL) is an important construct for understanding health outcomes for individuals with disabilities and chronic conditions. QOL is the *individual’s* perception of his or her position in life in relation to goals, expectations, and concerns, in the context of his or her culture<sup>47</sup> (as distinct from valuations of health care providers, administrators, etc.). Interventions, such as repairing a cleft lip to improve social adjustment, often aim at improving QOL. Families, providers, and researchers must struggle with the definition and measurement of QOL, especially in children, who cannot give informed consent. Such efforts are essential to weighing risks and benefits for children, as well as quantifying for health administrators and payers the impact of conditions and effectiveness of treatment. More research in this area is urgently needed.

*Oral health promotion in special populations.* The evidence for oral health promotion and disease prevention interventions in the general population are reviewed by the U.S. Preventive Services Task

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Force<sup>48</sup> and others and summarized by Crall. In the field of caries-prevention, good evidence exists for community water fluoridation, use of topical fluorides, and sealants. There is also evidence for the role of oral hygiene measures such as brushing and flossing for prevention and amelioration of periodontal disease. But data suggest that although knowledge can be imparted, changes in behavior are much more difficult to effect.

Studies of disease prevention or health promotion interventions in the context of special populations are very limited, and it may not be appropriate to extrapolate from general populations. It is difficult to aggregate data from this large, diverse population of individuals with varying conditions and social circumstances. Data collection at state and national levels is needed. The majority of the literature in the field of developmental disabilities reports clinical experience and anecdotes. Much work remains to be done in this area.

Health services research is also needed. The relatively high expenditures associated with children with special health care needs make them particularly vulnerable in the current health care environment.<sup>49</sup> It is important to understand fully the expenditures for neglected oral disease, to compare with costs of timely preventive interventions for these children. Overall, the economic impact of childhood dental disease is substantial, accounting for 20-30% of family child health expenditures. The costs for oral care incurred by health systems and families of children with special health care needs are not known.

*Developmental aspects of health promotion.* The development of health promotion behaviors is another area that has not been examined. Braveman discusses a behaviorist model for the acquisition of health promoting behaviors across the life span. There are problems with this approach, however, since immediate consequences for engaging or failing to engage in health promoting behaviors are typically absent. He postulates that children must therefore also learn these behaviors by modeling parental actions and/or attempting to meet parental expectations. Even with adults, knowledge of the importance of a health promoting behavior is insufficient to ensure its practice. Moreover, the presence of immediate consequences, such as coughing upon cigarette use or feeling sick after overeating, may not deter some strongly entrenched behaviors.

While this area has received very little attention in the normal population, even less is known about acquisition of health promotion behaviors among diverse populations, including those with neurodevelopmental disabilities or other special needs. A child's level of cognitive development, knowledge, and understanding of disease processes and health-

related experiences can affect this process. This is an important area of research for children with neurodevelopmental disabilities, who have heightened vulnerability and dependency in self-care skills and will face challenges in understanding and maintaining health as adults. The area of health promotion for children and adults with developmental disabilities is an emerging concern of advocates and others.<sup>6</sup>

### 3. What is a disability?

According to the Americans with Disabilities Act, a *disability* is “a physical or mental impairment that substantially limits one or more of the major life activities of such individuals, a record of such impairment, or being regarded as having such an impairment.”<sup>50</sup> Overall, health outcomes and quality of life for individuals with disabilities are a function of many bio-psycho-social determinants beyond the impairment itself, and models have been proposed to describe the relationship of these variables.<sup>51,52</sup> Improving outcomes for individuals with disabilities requires addressing many levels of health promotion activity—including community, environmental, health services, and societal factors, as presented above. Nitkin presents the conceptual framework for understanding disability utilized by the National Center for Medical Rehabilitation Research at the National Institute for Child Health and Human Development.

### 4. Understanding target populations

*Blending family and professional perspectives.* Understanding the needs of children with neurodevelopmental disabilities and other special health care needs requires the blending of child, family, and professional perspectives. Ideally, this would combine the best of evidence-based approaches (e.g., an analysis of health status that includes oral health status, needs and access issues of the targeted populations) with experiential knowledge gleaned from children, families, and providers that capture insights missing from data-driven analyses. Unfortunately, as noted, data on the general and oral health status and needs of individuals with neurodevelopmental disabilities and other special health needs are sparse.<sup>6</sup> Likewise, professionals have been slow to appreciate the value of the family perspective.

*Defining target populations.* Terminologies change with time and context. It can be difficult to define target populations, assess needs, allocate resources, and interpret studies. For example, several definitions of mental retardation are currently used, with professionals, advocacy groups, and researchers taking somewhat different views.<sup>53</sup> The federal government defines developmental disabilities broadly,<sup>54</sup> while states may use more restrictive definitions to limit the

*Understanding the needs of children with neurodevelopmental disabilities and other special health care needs requires the blending of child, family, and professional perspectives.*

*Changing definitions of target populations make it difficult to assess needs, allocate resources, and interpret studies.*

numbers qualifying for state aid.<sup>55</sup> Non-categorical approaches such as “children with special health care needs” aggregate many different groups for policy initiatives and health services research,<sup>56,57</sup> but there are limitations to this type of definition for individuals and sub-populations of children with varying problems and needs (see below). There are, in fact, advantages and disadvantages to each of these approaches to defining target populations. In current clinical usage, neurodevelopmental disabilities include a broad range of impairments in motor, sensory, cognitive, communication and social/adaptive functions of the nervous system that begin before age 18. The manifestations of the neurodevelopmental disability change as the child develops, thus it is not always possible to predict the permanency of such a condition in a child.

*Evolving context and meaning of neurodevelopmental disabilities.* The general concept of “neurodevelopmental disabilities” has evolved over the last 50 years from one of disease that can be cured or prevented to differences and delays in development due to diverse etiologies amenable to early intervention and educational programs to help children achieve their potential.<sup>58</sup> In the past, children with neurodevelopmental disabilities such as mental retardation were often institutionalized, but now community-based and family-centered services permit these children to be included in normal family and community life. Changes contributing to this progression include scientific advances in the understanding of mental retardation and other neurodevelopmental disabilities, shifts in social policies and values (particularly in the Kennedy era), deinstitutionalization policies for individuals with mental retardation, and advocacy efforts by parents and health professionals. Landmark legislation encompassed many of these changes in federal statutes and a *Surgeon General’s Report on Children with Special Health Care Needs*.<sup>59</sup>

*Prevalence of developmental disabilities and special health care needs.* The proportion of children with special health care needs in the United States is estimated at 18% of the population. This includes children with neurodevelopmental disabilities, but their numbers are difficult to estimate given evolving developmental processes throughout childhood. The overall number of individuals with mental retardation is estimated at 3% of the population worldwide,<sup>60</sup> and between 0.3–3.0% in the United States, with an overall average of about 1.0%.<sup>5</sup> The number of individuals with developmental disabilities in the United States is estimated to be 4 million.<sup>61</sup> Individuals with mental retardation are surviving longer, as are many children with special health care needs. This may somewhat increase the prevalence of these conditions.

*What families tell us.* Family participation is critical for shaping policies and practices that will be responsive to children’s needs. Families are the best advocates and experts on their children. They challenge health care systems, providers, and policy makers to address important issues. These include accessibility of dental offices, child-friendliness and family-centered care, respect for family privacy and individual differences, the need to share decision-making, sensitivity to cultural issues, attitudes and comfort of staff with children with special health care needs, communication and coordination among health providers and service integration, costs of care, difficulties related to adolescent transition, guardianship and long-term care, and the overall personal and social impact of health problems on individuals and families. The importance of stressing resilience, personal and family protective factors, and other positive aspects of adaptation to a disability or special health need cannot be over-emphasized.<sup>62</sup> Anderson and Clarren discuss some concerns raised by families and children.

*Children with neurodevelopmental disabilities and other special health care needs: diverse conditions and needs.* While children and families with special needs share many of the same general needs and concerns, differences between and within health conditions raise other important policy issues. The spectrum of these concerns should be addressed in service, policy, research, and training efforts.

- *Examples of services needed by all children with special health care needs.* Important services needed by all children with special health care needs include comprehensive, coordinated interdisciplinary team care that includes oral health concerns, primary care “medical homes” for coordination of health services and family needs, and regular oral health monitoring by a “dental home” or other appropriate source of oral health care. The scope of oral health issues—including dental, nutrition/feeding, oral-motor, and speech concerns—should be addressed by interdisciplinary health teams with appropriate oral professionals included on such teams. There is a need to address insurance coverage for interdisciplinary team care.

A problem-oriented approach can be extremely valuable for assessing clinical needs across diverse conditions, including mobility needs, medical problems, access issues, and psychosocial factors, as discussed by Nowak and Casamassimo.

- *Differences between health conditions.* Children with craniofacial conditions have significant oral health problems and needs that may exceed those of other children with special needs. Children with cleft lip and palate experience compromised health outcomes if essential dental, orthodontic, speech, and

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*While children and families with special needs share many similar concerns, differences between and within health conditions and families raise important policy issues.*

feeding interventions are not provided. Children with ectodermal dysplasias (born without teeth) require dental implants as a critical matter of function and quality of life. Few families have adequate insurance coverage for these needed oral interventions. Gaps in financing of oral health care particularly affect children and families with craniofacial conditions.

- *Differences within health conditions.* “Critical pathways” and care guidelines that describe typical children and the resources they require may be helpful overall, but they do not always serve an individual child’s or family’s needs. These kinds of guidelines should be considered as starting points only, and care should be individualized to meet child and family requirements. Particular problems arise when guidelines are used to limit needed care.
- *Research and policy implications.* The large number of rare and diverse conditions impedes needed research. Uncommon conditions may not receive sufficient attention to produce clinical breakthroughs and a solid evidence base. Important oral-systemic health linkages may go unnoticed or unstudied. Longitudinal studies are needed to accurately assess children’s health outcomes, and these are costly. As desirable as the move to evidence-based care is, it cannot be the sole criteria for funding health interventions at this time.<sup>63</sup> Trends to reimburse *only* evidenced-base care could disproportionately affect children with special health care needs.
- *Training implications.* The rarity and diversity of these health conditions complicates training of health professionals. Knowledgeable pediatric specialists are needed to work with primary care professionals, families, educational, and social systems. All health providers working with these children need the skills to interact across disciplines and systems to deliver coordinated care.

## **Responding to the needs of target populations**

*Child-specific definition of medical necessity.* How do we construct a health care system for all children that can include these diverse groups? A conceptual policy strategy that addresses the needs of all children is a “child specific” approach to needed health care. Such a framework takes account of the factors that distinguish children’s health needs from those of adults—children’s developmental processes, dependency, vulnerability, family/social/cultural context, relative socioeconomic disadvantage, and the diversity of childhood disorders.<sup>64</sup> This definition covers the broad array of services required by children, including oral health care,

preventive interventions and anticipatory guidance, and developmental therapies and treatments for acute and chronic conditions. This definition of needed health services is applicable to children with special health care needs and to all children. Such a framework also gives rise to specific implications for dental education<sup>65</sup> and research.<sup>66</sup> To eliminate oral health disparities in children, broad approaches must be used that target children within their developmental, family, social, and cultural context.

A similar child-specific standard of medical necessity exists in federal statute in the Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, a model of comprehensive health care that applies to dental as well as medical care but is only inconsistently enforced.<sup>67</sup> The authors of this legislation recognized that children's unique characteristics lead to the need for specialized benefits. Unfortunately, definitions of medical necessity are often used to ration health services, rather than to provide guidance on health interventions important to the child's overall health and development.<sup>57</sup>

*Need for integration of dentistry with medicine.* An approach to children's oral health that takes account of other medical, social and environmental variables requires increased integration of oral health into the rest of health and social systems serving families.<sup>68,69,70</sup> The theme of integrating dentistry with medicine and the rest of health care runs through the four intersecting areas—oral health, health promotion, disability, and the needs of children and families—that form the conceptual framework for this conference. Hopefully, this conference and the proceedings can serve as a strong impetus toward integration of oral health in training, research, service, and policy agendas for children with neurodevelopmental disabilities and other special health care needs.

*The theme of integrating oral health into the rest of health care, training, research, and policy runs through the conceptual framework for this conference.*

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# Full Recommendations

The recommendations from the conference on *Promoting the Oral Health of Children with Neurodevelopmental Disabilities* and other Special Health Care Needs address the five objectives of the Surgeon General's Call to Action in the context of these children and their families. The five objectives are: (1) change perceptions of oral health among health providers, policy makers and the public; (2) accelerate the acquisition and development of science and evidence-based data and apply sciences effectively to improve oral health; (3) build an effective oral health service infrastructure that meets the oral health needs of all Americans and integrates oral health effectively into overall health; (4) remove known barriers between people and oral health services; and (5) promote public-private partnerships to improve the oral health of those who still suffer disproportionately from oral diseases. Since these children suffer disproportionately as a consequence of our health system's general ignorance of oral health, recommendations will address both the overall lack of attention to oral health and specific needs of these children and families.<sup>1</sup>

## **I. Provide optimal education and training for families, health professionals, and the public.**

*(Objectives 1 and 3: Change perceptions of oral health among health providers, policy makers and the public; and build an effective oral health infrastructure that integrates oral health into overall health.)*

### **A. Families**

1. *Start oral health education early.* Reach out to parents (especially pregnant women) across health and social service systems. Discuss transmissibility of oral disease, the role of parental oral health, and the need for oral assessment of children by age 1.
2. *Emphasize that prevention of common oral diseases such as caries and periodontal disease is possible.* This can be an important motivator for families of children with disabilities and chronic conditions. Tie oral health prevention schedules to existing prevention schedules when possible (e.g., immunization schedules).
3. *Integrate oral health with other health information* such as nutrition and feeding practices, oromotor function, speech and language development, behavioral management, and medication

administration. Explain the interaction of oral health with the child's underlying health conditions. Build on *Bright Futures* oral health guidelines. Demonstrate simple examination techniques to help parents identify caries early.

4. *Tailor specific oral health instructions to the needs of the individual child, his or her health conditions, and family.* Children with special health care needs have diverse conditions and treatments, and although they share many attributes with each other and all children, they require individualized treatment plans.
5. *Educate parents in advocacy for healthy public policies and community actions* such as day care feeding practices, school lunch choices, soda machines in schools, accessibility of dental settings, insurance coverage for oral health, and community water fluoridation.
6. *Test efficacy of parent education programs* by obtaining baseline data and developing clear goals and outcome measures relating to oral health knowledge, attitudes, and practices.

### **B. Primary care medical providers**

1. *Educate health professionals in oral health promotion and disease prevention.* Integrate oral health components into undergraduate, graduate, and continuing education targeted at physicians, nurse practitioners, and physicians' assistants. Include development, structure, and function of oral and craniofacial structures; techniques for oral examination of infants and children; anticipatory guidance and other oral health promotion and disease prevention measures; risk-assessment; identification of oral problems and referral to oral health professionals; caries management and the role of fluorides; oral trauma and dental emergencies; oral-systemic linkages, including the impact of medications; and oral-nutritional interactions. Discuss the need for oral assessments by age 1.
2. *Highlight oral-systemic health linkages for children with special health care needs.* All providers caring for children with neurodevelopmental disabilities and other children with special health care needs should be aware of the oral health aspects of specific conditions such as cerebral palsy, Down syndrome, cleft lip/palate, congenital heart disease, diabetes, epilepsy, neoplastic diseases, bone/rheumatoid conditions, pulmonary disorders. They should also be aware of the oral impact of therapeutic regimens these children require, such as chemotherapies, immunosuppressants, anticonvulsants, antihistamines, antibiotics, gastric tubes, etc. Consider creating a compendium of oral

aspects of pediatric chronic disease tailored for primary and subspecialty medical providers.

3. *Increase opportunities for interdisciplinary collaboration* between health professionals, including dental, medical, nursing, nutrition, pharmacy, public health, and others.
4. *Emphasize family-centered, child-friendly, and culturally appropriate care for all children and families.* Address cultural factors (such as feeding practices) that interact with oral health and cultural interpretations of underlying health conditions.
5. *Teach public health competencies* as outlined in HP2010 objective 23-8. Relate health disparities to system-level factors as well as individual behaviors, including socioeconomic, cultural and environmental determinants of health. Apply public health approaches to the oral health context. <sup>2</sup>
6. *Develop policies and guidelines within professional associations* that articulate and support the role of primary care medical providers in oral health promotion of children and families.
7. *Work with appropriate professional credentialing bodies* to ensure oral health knowledge is included in board examinations, continuing education, and recertification requirements.
8. *Test efficacy of educational programs* by obtaining baseline data and developing clear goals and outcome measures relating to oral health knowledge, attitudes, and practices among trainees, faculty, and community practitioners.

### **C. LEND centers:**

1. *Ensure pediatric oral health assessments* are available as part of interdisciplinary evaluations in all LEND centers.
2. *Ensure pediatric dental professionals are on the faculty* in all LEND centers.
3. *Develop and implement regular educational initiatives and faculty development activities* in oral health for all trainees and faculty.
4. *Develop specific oral health education modules within each discipline.* Allow each discipline to “own” oral health issues and develop creative oral health education strategies relevant to each context. For example, for nursing, nutrition, occupational and physical therapists and speech and language trainees, address the inter-relatedness of oral health, nutrition, oromotor function, and systemic health. Instruct trainees in providing oral health information to parents and conducting oral and dental screening exams as appropriate. For social work and psychology trainees, discuss social and behavioral correlates of oral health, including

cultural factors, family stressors, and behavioral issues that affect children's oral health and access to care.

5. *As part of family-centered, culturally appropriate care, address cultural factors* that interact with oral health and cultural interpretations of underlying health and developmental conditions.
6. *Develop leadership training in larger policy issues* related to disparities in oral health status and access to care for special needs children, including oral health care delivery system issues, finance mechanisms, and research needed to understand and improve oral health and access to care for these populations.
7. *Test efficacy of educational programs* by obtaining baseline data and developing clear goals and outcome measures relating to oral health knowledge, attitudes, and practices among trainees and faculty. Determine if specific oral health training outcome components should be incorporated in follow-up of leadership education training programs.
8. *Explore potential in the other existing developmental disabilities centers for addressing oral health training*, as well as research, service, and policy. Other centers include the University Centers for Excellence in Developmental Disabilities Education, Research and Service<sup>3</sup> and the Mental Retardation Research Centers (MRRCs).

#### **D. Dental professionals**

1. *Educate all dental professionals in broad view of child health*, developmental, family, social, cultural, and environmental determinants of health.
2. *Emphasize family-centered, child-friendly, and culturally appropriate care for all children and families*. Address cultural factors (such as feeding practices) that interact with oral health and cultural interpretations of underlying medical and developmental conditions.
3. *Provide general dental students with direct experience with children, including children with special health care needs* with simpler oral health needs. Include important oral-systemic health linkages.
4. *Increase opportunities for inter-professional interaction and collaboration on teams* that include medical and other health professionals. Address communication skills needed for successful team work.
5. *Ensure adequate pediatric dentistry resources* to address needs of children with special health care needs, including those in hospital settings.

6. *Use allied dental professionals* to expand the work force available to promote oral health and prevent disease in all children, including those with special needs.
7. *Provide community service learning opportunities* for dental trainees that increase exposure to high-risk populations, including children with special health care needs such as in neurodevelopmental centers and preschools and other educational and institutional settings.
8. *Develop pediatric and general dentistry fellowship tracks* in care of children with special health care needs.
9. *Consider required PG-Y1 (a dentistry residency year)* to increase time for training in care of high-risk populations, including children with special health care needs.
10. *Teach public health competencies* as outlined in HP2010 objective 23-8. Relate health disparities to system-level factors as well as individual behaviors, include socioeconomic, cultural, and environmental determinants of health. Apply public health approaches to the oral health context, as described below.<sup>1</sup>
11. *Test efficacy of such educational programs* by obtaining baseline data and developing clear goals and outcome measures relating to oral health knowledge, attitudes, and practices among trainees and faculty.

#### **E. Other health professionals and child care workers**

1. *Educate obstetricians in oral health issues.*
2. *Educate other health professionals and child workers* in oral health, including nursing (school and public health), pharmacy, nutrition, social work, speech and language therapists, occupational and physical therapists, childhood education, and day care providers. Incorporate oral health goals and educational objectives in certifying exams for providers, school health policies, and day care practice guidelines.
3. *Develop specific collaborations between pharmacy and other dental and medical professionals* in order to educate providers on the optimal use of medications to minimize oral health risks.
4. *Test efficacy of such educational programs* by obtaining baseline data and developing clear goals and outcome measures relating to oral health knowledge, attitudes, and practices among trainees and faculty.

## F. Policy makers and the public

1. *Expand awareness of the importance of oral health among policy makers and the public* with consistent messages and targeted communication.<sup>4</sup>
2. *Measure effectiveness of oral health campaigns.*
3. *Follow through with policy objectives* directed to ensure oral health of all children.

## II. Foster research and translation of science related to oral health of children with special health care needs.

(Objective 2: Accelerate development of science and evidence base and apply sciences effectively to improve oral health). Research needs include:

1. *Epidemiological studies* on prevalence and types of oral health conditions in infants, children, and adolescents with neurodevelopmental disabilities and other children with special health care needs in community and institutional settings. Consider surveillance studies of certain groups of children with special health care needs. Monitor important health benchmarks including immunizations, oral evaluations, and dental referrals.
2. *Clinical trials and outcomes research* on oral health promotion and preventive interventions in children with special needs.
3. *Developmental and behavioral research* related to acquisition of oral health promotion practices in children and adolescents with special needs.
4. *Translation of science of caries prevention and medical management and other new bioscience discoveries into practice* for children with special needs.
5. *Oral-systemic health linkages* important to children with special health care needs, including oral impact of therapeutic regimens and primary prevention of low birthweight through treatment of maternal periodontal disease.
6. *Health services research*, including cost-effectiveness of interdisciplinary team-based models of care, costs of oral health care and neglected oral disease, and risk adjustment methodologies for children with special health care needs.
7. *Research on quality of life* impact of oral and craniofacial conditions, as well as resilience and positive adaptation in children with neurodevelopmental disabilities and other special health care needs and their families..

8. *Health promotion research, including system-level and policy changes to promote oral health for individuals with disabilities and special health care needs.*
9. *Oral-nutritional interactions.* Many studies could be considered in this area, such as food choices and eating patterns of children with special health care needs that affect their oral health, feeding practices of caretakers of children with special health care needs, the relationship between unhealthy early feeding practices and later harmful eating patterns, and behavioral and other factors associated with prolonged breast-feeding and bottle feeding that results in early childhood caries. Acknowledge the difficulty of promoting changes in eating and feeding patterns.
10. *Oral health components in other research programs* addressing common risk factors such as poor nutrition, obesity or related issues, or common target groups such as low-income pregnant mothers.
11. *Consensus conferences in key areas* such as health promotion research, the role of nutrition in maintaining oral health and preventing caries, and quality of life in oral and craniofacial conditions.
12. *Educational and communications research* on optimal means of changing knowledge, attitudes and practices of health providers, families, policy makers and the public.
13. *Mentored research experiences for LEND trainees* in oral health of children with special health care needs.

### **III. Create integrated service models and demonstration projects**

*(Objectives 3: Build an effective oral health service infrastructure that meets the oral health needs of all Americans and integrates oral health effectively into overall health.)*

1. *Integrate oral health into interdisciplinary team care for children with special health care needs.*
2. *Develop individualized treatment plans for children with special health care needs that include oral health in conjunction with families and interdisciplinary providers, including dental professionals. Balance competing priorities such as the need for frequent feedings with prolonged exposure to cariogenic nutrients.*

3. *Ensure all children with neurodevelopmental disabilities and other special health care needs have access to medical homes.*<sup>5</sup> Expand the medical home concept for children with special health care needs to include oral health promotion and disease prevention, screening, and referral to a dental home for appropriate dental care. Develop mechanisms to ensure delivery of such care; e.g., medical case management and managed care contract specifications.<sup>6</sup>
4. *Ensure all children with special health care needs have access to a dental home.* Consider a demonstration project for special needs children using the ABCD<sup>7</sup> model of community access to dental care.
5. *Develop guidelines* for appropriate oral exams, anticipatory guidance and screening for children with special health care needs by primary care medical providers as a part of EPSDT.<sup>8</sup>
6. *Ensure presence of adequate dental and oral health services* at children's hospitals and tertiary care centers that serve as medical and dental safety nets for children with special health care needs.
7. *Develop integrated service and training models* that include pediatric dental faculty and trainees in regular ward experiences as well as oral health assessments as part of comprehensive pediatric evaluations in these settings.
8. *Reach out to children and families across the full range of health, social service, and education systems*, including primary care settings, community health clinics, children's hospitals and tertiary care centers, neurodevelopmental centers, Head Start, and WIC centers, among others.
9. *Use interdisciplinary providers and allied health professionals* to integrate oral health systems (in #8 above), including dental hygienists, nurses, dietitians, speech and language therapists, and occupational and physical therapists.
10. *Ensure outreach, case management, and other enabling services for children with special health care needs* to ensure children receive needed oral health care.
11. *Address enabling services needed to ensure cultural competency of systems dealing with children and families with special needs.*
12. *Ensure adolescents with special health care needs are transitioned to the full range of adult health care and enabling services, including oral health care.*

## **IV. Support critical policy change and standards of care.**

*(Objective 4: Remove known barriers between people and oral health services.)*

1. *Ensure health insurance coverage for all children, including those with special health care needs.*
2. *Develop child-specific definitions of medical necessity that include oral health promotion and preventive care; treatment of oral and craniofacial problems including needed orthodontic care, appliances, and implants; coverage of general anesthetics when needed for oral health care; and interdisciplinary team care. Hold health systems accountable.*
3. *Develop incentives that encourage dental professionals to work with children with special health care needs such as loan forgiveness programs and risk-adjusted rates for more time-consuming and difficult care provided for special needs children.*
4. *Develop a comprehensive oral health promotion policy agenda that includes these and other policy innovations.*
5. *Consider policies that facilitate adolescent transition to adult health services including oral health care, assistance with oral health home practices, promotion of healthy diet, and abstinence from tobacco.*
6. *Address important barriers to care for older individuals with disabilities and special health needs, such as complex guardianship and other legal issues.*

## **V. Use partnerships to address oral health disparities in children with special health needs.**

*(Objective 5: Promote public-private partnerships to improve the oral health of those who still suffer disproportionately from oral diseases.)*

1. *Ensure participation of families as partners in health care and policy planning.*
2. *Develop collaboration among and across LEND programs and other MCHB-funded leadership training programs, Schools of Dentistry, Schools of Public Health, governmental and regulatory agencies, and private non-profit and corporate entities as appropriate to promote oral health training, service, research, and policy agendas for these populations of children; include culturally diverse perspectives.*

3. For example, partner with food and pharmaceutical industries and regulatory agencies to develop labeling that indicates cariogenicity of foods and medications and formulate sugar-containing liquid or chewable medications for children.

## Endnotes

1 These recommendations reflect a broad range of conference discussions and do not represent the institutions or agencies sponsoring this conference. In addition to *Oral Health in America: A Report of the Surgeon General* (<http://www.nidcr.nih.gov/sgr/sgr.htm>) these recommendations have been influenced by *Bright Futures* ([www.brightfutures.org](http://www.brightfutures.org)) and *Achieving Success for All Children and Youth with Special Health Care Needs: a 10-Year Action Plan to Accompany Healthy People 2010* (Maternal and Child Health Bureau).

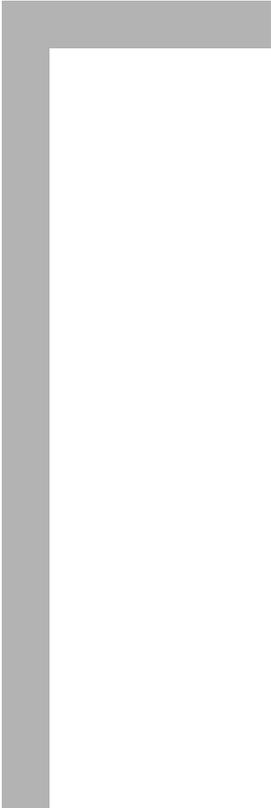
2 <http://web.health.gov/healthypeople/document/html/volume2/23phi.htm>

3 Formerly University Affiliated Programs, these programs are funded by the Administration on Developmental Disabilities, Agency for Children, Youth and Families; MRRCs are funded by the National Institute of Child Health and Human Development, National Institutes of Health (see Appendix).

4 See for example the successful Watch Your Mouth Campaign, a public-private partnership between Washington Dental Service and the University of Washington School of Public Affairs. <http://www.kidsoralhealth.org>

5 The American Academy of Pediatrics (AAP) defines a medical home as the provision of care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. The medical home implies joint accountability between the physician and the family. Providing a medical home means addressing the medical and non-medical needs of the child and family. For the primary care physician, this role may involve identifying and making referrals to the community, state, and federally funded resources that will benefit the child and family (Palfrey J. and Haynie M. Medical home program for children with special needs. AAP News, 1996).

6 CHSRP Reports. Sample purchasing specifications for Medicaid pediatric dental and oral health services: March 2000. Available at: <http://www.gwu.edu/~chsrp>.



7 The ABCD (Access to Baby and Child Dentistry) program engages general dentists in care of infants and young children after special training. Milgrom P, Hujoel P, Grembowski D, Ward JM. Making Medicaid Child Dental Services Work: A partnership in Washington State. *Jr Am Dent Assoc.* Oct 1997; 128: 1440-1446

8 Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, Social Security Act. Section 1905 (r).

## Health Promotion for Populations with Special Needs

Ruth Nowjack-Raymer, MPH, Ph.D

Health promotion is a term that is widely used but often misused in the United States to denote activities designed by health professionals to educate individuals or the public about health behaviors. Health promotion in actuality is much more than health education and involves sectors well beyond those focused on health care. Several important conceptual frameworks have emerged since the 1960s that help to articulate the multifaceted nature of health promotion. The concepts of health promotion that are fundamental to the deliberations of this conference and the formulation of research and training agendas are those that answer the following questions:

1. What are contemporary definitions of health? The World Health Organization developed a positive concept emphasizing social and personal resources, as well as physical health.
2. What are contemporary definitions of oral health? Today, “oral health” includes the vast array of structures of the oral cavity and the contiguous structures known as the craniofacial complex and their sensory, digestive, respiratory, structural, and emotional functions.
3. What is quality of life within the context of oral health? This is the extent to which people identify that their teeth, mouth, dentures or other aspects of the craniofacial complex affect their ability to eat a full range of desired foods, the level of societal interaction that they have, the ability to speak clearly, and the level of self-confidence.
4. What then is health promotion? The World Health Organization (WHO) defines health promotion as “a process that enables people to increase control over the determinants of health and thereby improve their health.”
5. What are examples of oral health promotion actions that may have implications for training and research agendas for children with special needs? Health promotion actions include:
  - **Developing personal skills** such as through adaptive approaches to oral hygiene and preventive regimens.

*Health promotion is more than health education directed at personal behaviors. Health promotion involves individuals, communities, and the larger society and necessitates a broad range of actions.*

- **Creating supportive environments** by ensuring that the physical and social environments in which we live maximize the possibility of leading healthy lives. These supportive environments can be at the level of the family, the neighborhood, the community, or through the population health approach and common risk/health factor approach. One example might be availability of sucrose-free medications.
- **Building healthy public policy** by working to ensure that all levels of organizations and government take into account the potential health effects of the policies they develop. Examples might include healthy feeding practices in daycares and greater use of allied dental and primary medical practitioners to perform simple oral health promotion interventions.
- **Strengthening community action** by identifying priorities, planning strategies, and implementing actions that will improve health.
- **Reorienting health services** by helping the health care system to expand beyond the treatment of disease and provision of clinical services to promote the health of individuals and communities in other ways.

### **Conclusion**

Health is more than the absence of disease. Health promotion is more than health education directed at personal behaviors. Health promotion involves individuals, communities, and the larger society and necessitates a broad range of actions. Health promotion actions require interdisciplinary and trans-disciplinary approaches and health care workers with multiple skill packages to carry out diverse roles. The health promotion approach can serve as a catalyst for research and training agendas and changes that will benefit not only the health and oral health of children with neurodevelopmental and other special needs but also that of the general population.

(This paper is presented in its entirety as an attachment to this report.)

# Conceptual Frameworks for Disability

Ralph Nitkin, PhD

## Challenges of assessing children's health status

There are many challenges to assessing children's health status. Children have greater dependency on family and community context, and are experiencing the changing landscape of developing physical and behavioral repertoires. Disability can impede physical, behavioral, and emotional development, which, in turn, limits environmental interactions further affecting the developmental trajectory. Another issue is that studies of children often rely on proxy reporting by parent or caregiver—especially for very young children or those with more severe disabilities. The child's values, assessments, and goals (i.e., quality of life) may differ from those of the adults. Finally, there is the challenge of developing age- and ability-appropriate testing.

## Multi-dimensional approach

Children with disabilities should not be categorized by their diagnoses alone, but rather assessed across *domains* of impairment, function, disability, and environment. Environments can be either positive (e.g., assistive technologies, medications) or negative (e.g., structural barriers, limited participation). The table below outlines a conceptual framework for disability research developed by the National Center for Medical Rehabilitation Research (NCMRR). NCMRR, which is located within the National Institute of Child Health and Human Development (NICHD), is the primary focus for rehabilitation research at the National Institutes of Health (NIH). Researchers may be interested in the four NCMRR regional research networks, one of which is based at the University of Washington's Center on Human Development and Disability.

## Considerations for the dental community

Dental and oral problems may result from primary (e.g., developmental oral defects) or secondary (e.g., more limited behaviors and decreased autonomy) consequences of developmental disabilities. Access to good oral health can be impeded by physical barriers in the dentist's office (constraints of the dental chair, limited wheelchair access) as well as cognitive and motor issues (e.g., limited communication skills and/or reduced cognitive understanding, spasticity and movement disorders, altered pain sensation and management, even breathing or swallowing abnormalities). Many of these issues are compounded by socioeconomic factors, and particularly impact children from ethnic minority

*Disability can impede physical, behavioral, and emotional development, which, in turn, limits environmental interactions further affecting the developmental trajectory.*

backgrounds. Moreover, children with disabilities are more likely to be reliant on Medicaid. As an early line of contact with the families and caretakers, dental professionals have increased responsibility to aid in the management of potential co-morbidities involving speech, language, breathing, and eating. Children with disabilities may be candidates for increased prophylactic care because they are likely to have decreased and more irregular contact with dentists in later years.

### Recommendations

Potential recommendations include the development of unique health care resources for children with disabilities, elimination of inappropriate liability issues, emphasis on a more integrated approach to treatment of the individual, increased training and resources for the oral health community, and outreach to families with disabled children and their advocacy community.

#### Two Approaches to Disabilities

Model	Underlying Cause/Etiology	Limitation at Body Level	Limitation at Personal Level	Limitation at Societal Level	Context
NCMRR	Pathology/ Pathophysiology	Impairment	Functional Limitation	Disability	Societal Limitation
ICIDH-2*	Health Conditions	Body functions and structures	Activities	Participation	Environment

\* 1999 WHO International Classification of Functioning and Disability.

**Pathophysiology:** The interruption of or interference with normal physiological and developmental processes.

**Impairment:** The loss or abnormality of cognitive, emotional, physiological, or anatomical structure or function, including secondary losses/ abnormalities, not just those attributable to the initial pathophysiology.

**Functional Limitation:** A restriction or lack of ability to perform an action in the manner within the range consistent with the purpose of an organ or organ system.

**Disability:** The inability or limitation in performing tasks, activities, and roles to levels expected within physical and social contexts.

**Societal Limitation:** The restriction, attributable to social policy or barriers (structural or attitudinal) that limits fulfillment or denies access to services and opportunities for full participation in society.

## Faces of Children and Families

**Sterling K. Clarren, MD**

I have had the privilege over the years of talking to many families and children impacted by neurodevelopmental conditions, craniofacial conditions, and other special health care needs. Today I wish to share with you some of what I learned from talking to families of children with many different sets of health issues, feelings, and behaviors.

### **I. Facing the past: understanding etiology**

I cared for a child who was affected by Down's syndrome. The etiology of the condition is known to be genetic and not related to anything the mother did before or during her pregnancy. Despite my reassurances on this point, the parents were beset by guilt. Each family must come to grips with this issue in the best way they can, but it is clear they must get over it to move on, or this will interfere persistently with the care of the child.

An acquaintance had Crouzon syndrome, another genetically-determined condition. Though relatively well adjusted, when it came time for her to start a family, she was very worried her child would have the condition—a 50% risk for her. These issues did not surface until child-bearing years, and despite her husband's acceptance of her and the condition, she had lots of trouble accepting that a child of hers could have the same condition.

Fetal alcohol syndrome (FAS) is a biomarker for a world of hurt, I have learned from my work in this field. I believe no mother ever wanted to create a child with FAS. But these mothers have a 100% history of severe abuse; 80% have co-morbid psychiatric diagnoses, often 4 or 5. Children with FAS go on to have life problems and are more likely to be abused themselves, even when out of their biologic homes.

### **II. Facing inward: Goldenhar syndrome**

Since face is a reflection of self, this developmentally-determined congenital asymmetry of the face (which can also include malformed ears and hearing loss) can have an impact on self esteem. Surgeries made one teenage girl "look better," but self-image is much more complex than that. She became depressed after surgery, although she was considered attractive, and had many dates and friends. Looking 'better' did not improve her self-esteem, which is much deeper. She required psychological attention.

*Promoting the overall health of children with special needs means teaching children how to be resilient and cope with the world's reactions to their differentness—which many do, incredibly well.*

### **III. Facing forward: velocardiofacial syndrome (VCSF)**

Like many children with neurodevelopmental disabilities, children with VCSF really do not look all that different, although speech is usually abnormal. Most have learning and/or behavior problems, like this youngster. In addition, up to one-third develop schizophrenia later in life. This condition is caused by a deletion of critical genetic material. Families whose children have this condition need long-term comprehensive interdisciplinary care to address the many speech, educational, and mental health issues that arise, including the stress of a potential severe condition arising in the future.

### **IV. Facing outward: Wardenburg syndrome**

A boy with hyperterlorism and prominent epicanthal folds demonstrated severe acting out and school failure. His behavior and school performance improved after surgery, although it only led to a modest change in facial appearance. When asked how he was handling school and comments other kids made, he said he had a new strategy. Now he was able to point to the facial scar and say to people, “I was in a motorcycle accident,” and that seemed to be acceptable. It’s OK to have an accident; but **not OK** to be born with a birth defect. This is all about cultural expectations, and what children with facial differences learn to cope with—many of them very successfully.

Promoting the overall health of children with these conditions means teaching children how to be resilient and cope with the world’s reactions to their differentness—which many do, incredibly well. Long-term outcome studies on children with craniofacial conditions (including our own longitudinal study) have noted that there is a surprising lack of correlation between magnitude of the facial problem and psychosocial adjustment. All children and families with special needs should have access to ongoing comprehensive care to address these and other issues.

# Parents as Partners for Children with Special Health Care Needs

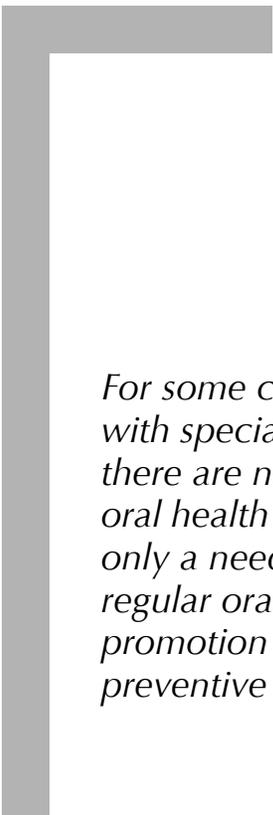
**Betsy Anderson**

Families are children's first and best advocates, providing and overseeing their children's health care and development. Family Voices is a national grassroots network of families and friends who speak on behalf of children with special health care needs and help develop and distribute materials for families to promote their well-being. Family Voices encourages families to involve their family dentist in helping them to raise healthy children.

The organization has identified the following oral health issues for families:

- Oral health is more than teeth—it is also mouth, face, nutrition, speech, chewing, swallowing, appearance, well being, and confidence.
- Perceptions of oral health and what can be done may be different from what parents learned growing up. New dental procedures include sealants, cosmetic treatments, and pain management.
- Experiences and beliefs about oral health vary among cultures (especially immigrants).
- Families play the most important role in day-to-day care.
- Barriers to effective care include the high costs of care, lack of information about how to get services covered, and the red tape and delays that families face when sorting out such issues as breadth of coverage, pre-approvals, and co-pays.
- Families face the problem of limited provider acceptance, especially for those with Medicaid or certain dental plans.
- Provider roles include providing information and support to children and families, and practicing family-centered care.
- Families need communication and coordination among child health providers—including dentists, pediatricians, and others.
- Dental care is not typically part of regular health insurance, which conveys a confusing message to families about the importance of oral health.

*Families need communication and coordination among child health providers—including dentists, pediatricians, and others.*



*For some children with special needs, there are no special oral health issues, only a need for regular oral health promotion and preventive care.*

Following are other oral health issues for children with special health care needs:

- Accessibility, modification, and accommodation are prerequisites for care. Some dental offices, for example, are not in compliance with the Americans with Disabilities Act.
- Staff members have variable attitudes and comfort levels in caring for children with special health care needs.
- Staff training should address information, support, and specific treatments for children with special health care needs.
- Appropriate recommendations are needed as to which treatments and procedures generally require anesthesia and which do not.
- Costs are always at issue—for treatment, equipment and supplies, and other health care costs families face.
- Under managed care, some procedures may be denied, thus requiring families to appeal.
- Separate dental services require families to coordinate and schedule additional appointments that must be coordinated with other health care visits and therapies.
- Coordination with children's other health care professionals is necessary to provide quality, family-centered care.
- Oral health professionals should be advocates for children's health care and services.

Remember that for children with special needs, there are no special oral health issues, only a need for regular oral health promotion and preventive care as part of comprehensive health care.

# Dental Caries and Periodontal Disease Made Simple

By Joel H. Berg, DDS, MS

This paper will briefly describe the rudiments of dental caries and periodontal disease, as well as their effects on systemic health.

## Dental caries

Dental caries, which affects nearly 97% of the population, is the process of demineralization and subsequent cavitation in teeth. It is caused by acid production when oral bacteria ferment carbohydrates. Each time fermentable carbohydrates are presented to the mouth, and therefore to the oral flora, they will be metabolized into acids that have the potential to demineralize enamel when the pH drops to 5.5. This pH drop occurs immediately after any kind of “sucrose challenge.” Normally, salivary buffering capacity along with the remineralization potential of fluorides will reverse this demineralization process and will prevent the formation of an actual “cavity.” The frequency of sugar challenge is important in the initiation and progression of dental caries. The more acid challenges to the enamel surface relative to remineralizing opportunities, the greater the chance that an actual surface defect will develop.

Medical providers are generally the first to examine the mouth of a child and therefore have the first opportunity to recognize dental disease. The risk of dental caries includes the interplay of three principle factors: the host (saliva and teeth), the microflora (oral biofilms), and the substrate (diet—content and frequency of exposure), as well as time. Risk assessment takes into account these and other factors.

There are significant associations between caries experience and socioeconomic status, ethnicity, and sucrose content of the diet. Intervention with preventive programs, including appropriately modified diet, oral hygiene, and fluoride exposure, can positively affect the caries experience of children. There is a renewed awareness of the benefits of remineralization with appropriate use of fluoride in various forms and xylitol-containing chewing gum. The recent implementation of fluoride varnishes is an appropriate means of delivering a low dose/continuous release mode of fluoride.

*There are significant associations between caries experience and socioeconomic status, ethnicity, and sucrose content of the diet.*

*Oral hygiene is the most important factor in the prevention of gingivitis and periodontitis in children.*

### **Periodontal disease**

Periodontal disease is a chronic bacterial infection that affects the supporting structures of the teeth, including the gums and the bone supporting the teeth. If left untreated, in some cases it can progress to tooth loss. The mildest form is gingivitis, or inflammation of the gingiva (gums). Plaque bacteria attach to the tooth surface above and below the gum line, and this can trigger a host inflammatory response. This host response causes the breakdown of tissue.

Early-onset periodontitis affects individuals 35 and younger. It is characterized by rapidly progressive bone/attachment loss and usually occurs with defects in the host immune response. The most rapidly progressive form of early onset periodontitis is generally associated with white blood cell (neutrophil) dysfunction, which allows rapid progression of the disease.

Children with insulin-dependent diabetes mellitus are at greater risk of periodontal disease, particularly when their diabetes is not well controlled. Gingivitis is the predominant form of periodontitis in children and adolescents, and gingivitis will progress to periodontitis more quickly in diabetic children. Healthy children rarely have cultivable organisms responsible for periodontal disease (*A. actinomycetem-comitans* and *P. gingivalis*), whereas these organisms are cultivable in more than 20% of children exhibiting true periodontitis. Youth who smoke or use spit tobacco are also at risk for periodontal disease. Children on phenytoin and certain other drugs are at risk for gum hyperplasia and gingivitis, but these can be minimized with good oral hygiene.

Oral hygiene is the most important factor in the prevention of gingivitis and periodontitis in children. The removal of plaque and calculus is essential in averting the acute inflammatory response; treatment of gingivitis and periodontitis in children consists primarily of professional cleaning. If the disease has progressed to the level where attachment loss exists, then surgical excision of inflamed tissues may be necessary.

(This paper is presented in its entirety as an attachment to this report.)

# Historical and Research Perspectives

Arthur J. Nowak, DMD, MA

Paul S. Casamassimo, DDS, MS

## Introduction

Understanding oral health research issues for children with neurodevelopmental disorders and other special health care needs requires a historical perspective and a conceptual framework. Today we have a largely empirical base of information to support care of these children. Practitioners, whether specialty or general practice, have been immersed in techniques that have been perpetuated without benefit of scientific validation. A low priority for oral care of special populations, a limited workforce, and one focused on clinical needs have impeded research. Federal priorities for dental research, while demonstrating a long-term interest in basic science related to the craniofacial area, only recently have taken on disparities that include other special needs populations.

## Educating dentists to care for children with special needs

Beginning in the 1920s, some dental students treated patients in hospitals, asylums, and homes for the “incurable.” By the 1930s, some academic institutions were promoting post-doctoral programs in pedodontics. During the next 25 years, graduate programs in pedodontics grew and continued to provide didactic and clinical experience in care of children with special health care needs as well as other children. With the formation of the American Academy of Pedodontics in the 1940s and the establishment of Academy of Dentistry for the Handicapped (ADH) in the 1950s, members with mutual interest had organizations to rally around and promote pediatric comprehensive preventive programs, behavior management, early recognition of developing malocclusions, and treatment for children with special health care needs. In the 1960s, the federal Bureau of Maternal and Child Health increased the number of dental training programs, but the budgets for these programs fluctuated dramatically. During this time, local and regional programs funded either by states or local advocacy organizations trained dentists to treat special patients.

The results of two surveys of dentists, one in 1989 and another in 1998, suggest that pediatric dentists are overwhelmingly involved in treating

*Federal priorities for dental research, while demonstrating a long-term interest in basic science related to the craniofacial area, only recently have taken on disparities that include other special needs populations.*

*A lack of training, reluctance to treat special patients, and inaccessible buildings and offices all decrease the dentists' accessibility to special patients.*

patients with special health care needs as a routine, and that the needs of these patients have remained high over the years in practice. In addition, advocates for special patients continue to report physical barriers to access despite passage of the Americans with Disabilities Act. Finding a dentist to treat special patients also remains difficult in many communities. A lack of training, reluctance to treat special patients, and inaccessible buildings and offices all decrease the ability of special patients to access care. Finally, pediatric dentists, though few in number, disproportionately serve the special needs population when compared with other dentists.

### **What do we know and how good is the information?**

Research into children with special health care needs is complicated by ever-changing definitions of the population, and the categorizing of existing literature in functional terms. A problem-oriented approach that defines the broad issues appearing most frequently in clinical care and research includes the following: accessibility (physical as well as provider willingness to accept patients); psychosocial obstacles; financial issues (including the effects of disabilities on parental employment); communication issues; mobilization and stability including patient positioning for care; prevention measures; treatment planning (includes issues such as clinical pathways); medical status; and continuity of care. Most research into care of children with special health care needs is largely descriptive and the body of treatment literature is based on expert opinion and empiricism (see Table 2 in full paper).

In summary, the education of dental personnel in care of children with special health care needs has evolved over the last half century. Current training programs may be inadequate to provide the number of skilled providers necessary to treat these children.

(This paper is presented in its entirety as an attachment to this report.)

## Evidence-based Approaches to Oral Health Promotion

James J. Crall, DDS, ScD

This paper discusses the prevalence of common oral and craniofacial conditions in children with special health care needs, and their use of oral health services. It reports on evidence for the effectiveness of various oral health promotion modalities and raises environmental and policy issues that warrant attention.

No national studies have been conducted to determine the prevalence of oral and craniofacial diseases among the various populations with disabilities. Data on the oral health of and utilization of services by children with special needs are limited to studies of individuals with a particular condition (such as mental retardation [MR]), or aggregated for individuals whose diagnoses vary. The majority of evidence suggests that individuals with MR have more untreated caries, gingivitis and periodontitis than those in the general population. Individuals with Down Syndrome are especially likely to have gingivitis compared with the general population. Some studies suggest individuals with mild MR, who are less likely to be closely supervised, have worse oral disease. Children with special health care needs are prone to develop malocclusions as a result of abnormal developmental processes and muscle function. An estimated 2.9 million children visited emergency rooms for dental or oral injuries between 1997 and 1998. It is unknown how many of these were children with developmental delays, who may be more prone to oral trauma.

Studies generally indicate that individuals with mental retardation or other special health care needs, especially those residing in smaller community-based facilities, do not receive adequate dental health care. Nearly two-thirds of community-based residential facilities report that inadequate access to dental care is a significant issue. Research efforts on health care service use by this population are scarce, or focus on non-representative samples. Results of the 1994-95 National Health Interview Survey on access to care and use of services by children with special health care needs indicate that 8.1% of these children under age 18 were reportedly unable to get needed dental care, with roughly 6% of those with public or private insurance having difficulty, and nearly 24% of those who were uninsured.

*There are few studies demonstrating the efficacy, cost-effectiveness, or modifications necessary to extend research findings to populations of children with special health care needs.*

## **Oral health promotion framework**

Effective health promotion activities can be used to alter an individual's or population's environment or behaviors. Environmental changes can be in one's physical or social environment, or in policies and programs that promote better oral health. Changes in behaviors can include activities performed by the individual or by others responsible for the care of the individual (parents, group home workers, etc.). Oral health promotion can target different levels in society: individuals, families, groups, organizations, entire communities, or even society as a whole. Similarly, oral health promotion can target different outcomes: changes in lifestyles, social practices, environment, policies, development or organization of resources, etc.

## **Evidence-based oral health interventions**

Effective interventions have been summarized and include community-based efforts such as water fluoridation, fluoride rinses, and dental sealants; health behaviors such as use of fluoride toothpastes and plaque control measures; clinical approaches such as topical fluoride applications and chlorhexidine gels. Effective approaches may combine fluoride, chlorhexidine, sealants, etc., particularly in high-risk individuals. Further studies are needed to define the best combinations.

Data are lacking to support effectiveness of nutritional counseling and mass media campaigns. Educational interventions have been shown to change knowledge and attitudes, but not necessarily behaviors. A host of broad environmental factors and policy issues also must be considered, including individualized health promotion education, education of health care providers, surveillance, and health services and policy-related research.

## **Summary and conclusions**

Available evidence provides considerable support for a variety of oral health promotion activities that have been shown to be successful. There are, however, few studies demonstrating the efficacy, cost-effectiveness, or modifications necessary to extend these findings to populations of children with special health care needs. Millions of children with special health care needs have not fully benefited from these investments in basic research and product development. Similarly, attention must be directed to research and policy development that can extend the benefits of the prior investments to those who are arguably most vulnerable to oral diseases and conditions.

(This paper is presented in its entirety as an attachment to this report.)

# Special Olympics/Special Smiles

## Mark Wagner, DDS

The Special Olympics Healthy Athletes initiative works to improve athletes' ability to train and compete in Special Olympics. The program's key objectives are to:

- Improve access and health care for Special Olympics athletes at event-based health screening clinics.
- Make referrals to local health practitioners when appropriate.
- Train health care professionals and students in the health professions about the needs and care of people with mental retardation.
- Collect, analyze, and disseminate data on the health status and needs of people with mental retardation.
- Advocate for improved health policies and programs for people with mental retardation.
- Implement specific programs that include dental, vision, hearing, and fitness screening.
- Promote health to emphasize good habits and fitness as a priority for athletes.

Special Olympics Special Smiles is an oral health initiative within the Special Olympics Healthy Athletes program to improve access to dental care for people with special needs and to raise the public and dental community's awareness of the oral health problems these individuals face. The program goals are to:

- Conduct dental screenings and education programs at Special Olympics events.
- Provide dental education programs, including continuing education.
- Serve as advocates on standards of quality of care.
- Maintain and provide to all Special Olympics athletes lists of dental professionals who care for people with special needs.

*Special Olympics, Special Smiles is an oral health initiative to improve access to dental care for people with special needs and to raise awareness of the oral health problems these individuals face.*

A sample of athletes screened recently points to high levels of unmet oral needs among special populations of all ages and reveals the potential for such private groups to contribute to training, research, and service needs.

**Table 1: Oral health of athletes in the 2000 Special Olympics\***

	<b>N</b>	<b>Percent</b>
Clean teeth less than once a day	9,338	12%
Have tooth pain	9,303	9%
Have untreated decay	9,027	26%
Have filled teeth	9,042	61%
Have missing teeth	8,993	22%
Need urgent treatment	9,145	11%
Have injuries to teeth	9,023	13%
Have signs of gingivitis	9,131	42%
Have sealants	9,021	14%

\*Screening data collected by Special Olympics, Special Smiles program from over 34 sites during the 2000 season. Age range from 8 to 81 yrs, mean age being 23.6.

Standard deviation +/-12.7 percentage points for each parameter measured.

## Development of Health-promoting Behaviors

**Norman S. Braveman, Ph.D.**

This paper provides a framework for a research agenda on the developmental aspects of health promoting behaviors.

A recent literature review on the influence of family on oral health concludes that the earlier oral health care habits are established in a child's life, the greater the likelihood that they will be maintained. Yet, there are many unanswered questions behind this assertion. The behavioral mechanisms underlying the acquisition of even simple health promotion behaviors—such as hand-washing or tooth brushing—are not fully understood. It is necessary to understand health promotion behaviors in a normally developing child before attempting to understand them in a child with a disability.

### **ABCs of behavior**

One approach for analyzing behavior is the ABC model, where A, B, and C are the antecedent(s) to behavior, the behavior(s) itself, and the consequence(s) of the behavior, respectively. Antecedents may be discrete stimuli (hunger) or more complex conditions (e.g., socioeconomic status). Antecedents set up conditions for the behavior to occur, which leads to consequences, which can modify the antecedents or the behavior. Consequences can also become antecedents for other behaviors, and so on. Effective reinforcers are usually temporally or spatially related to the behaviors, or seem logically related (i.e., stomachache after eating a certain food). Yet tooth brushing, like other health promoting behaviors, does not always have an immediate and discernible effect, does not always prevent disease, and does not guarantee dire consequences with non-use. Other factors are probably also important, such as the young child seeking the parent's approval, the child's cognitive level, understanding of disease processes, or health experiences. Families can influence reactions towards oral health by instilling fear or acceptance of the dentist in their child, or by influencing the child's other health beliefs. Understanding the relationship between child and adult health promotion behaviors will require longitudinal studies, and none exist in the literature.

*Research should address acquisition and maintenance of health-promoting behaviors in childhood, including how disabilities or chronic conditions alter outcomes.*

### **The role of cognitive development**

The developing child's concept of illness has been understood within a Piagetian framework. Children acquire an understanding of the concepts of illness as they move from magical thinking to concrete thinking to formal abstract thinking. The child initially believes the illness is a punishment; later s/he begins to see more personal control in the illness/recovery process, and to develop an understanding of disease processes. This research, which is considerable, has not really addressed the issue of cultural, ethnic, or gender influences. Still more complex is understanding how a disability or chronic illness interacts with other variables in acquiring health promoting behaviors.

### **Links between early health promotion and adult health**

Research has demonstrated the relationship between socioeconomic disparities and health outcomes. It may be possible to use this framework to include early life factors and developmental issues in a multifactorial model of health status. Theories linking childhood and adult health outcomes include the *latency or critical period* model, in which early factors affect later outcomes regardless of intervening factors (e.g., birthweight, placental size). The *pathways* model considers that early events set the individual on a life-long developmental trajectory leading to a different adult health outcome. The third model views the *cumulative effects* of different influences over time, based on the specifics on the intervening factors. The enduring effects of socioeconomic level on health outcomes, for example, can be explained using either of the second two models. (These models are not necessarily mutually exclusive).

### **Research needs and opportunities**

Important research areas should be addressed including studies of acquisition and maintenance of health promoting behaviors in childhood; pathways between child and adult health promoting behaviors, longitudinal studies throughout the life span; and qualitative and quantitative research on the actual impact of health promoting behaviors on long-term health outcomes. This research must be done in a manner that considers critical issues related to diversity, and how the presence of a disability or chronic condition alters outcomes.

(This paper is presented in its entirety as an attachment to this report.)

# Oral Health-promoting Behaviors

Susan E. Cheffetz, DMD, EdM

Although children with special health care needs represent about 18% of the pediatric population, very few studies have examined the oral health-promoting behaviors that affect these children. Research shows that dental care is their most prevalent unmet health need. Practical issues affecting their dental treatment can be categorized as physical, cognitive, or emotional, and they all may require modifications in the delivery of dental care. Physical conditions may affect access to the dental office, the dental treatment itself, or home care practices. Emotional difficulties may include fear of the dentist, dental treatment, or any interventions involving the mouth. Cognitive conditions may affect the child's developmental skills and, therefore, ability to understand situations in the dental office, as well as home care issues.

The child's oral health-promoting behaviors are affected by the child, the parent, the practitioner, and the service system.

- The young child's role in oral health-promoting behaviors is to cooperate with the dentist and with home care. Older children can carry out health promoting behaviors more independently as age and abilities permit. Children's knowledge and understanding play a very important role; specifically, knowledge and understanding of oral diseases, their causes, and prevention.
- Parents' behaviors are critical in determining the quality of care that the child receives. Parents of children with disabilities may not be able to put time and effort into their child's dental needs in the midst of dealing with many other appointments and health issues for their child.
- The dentist is the practitioner most involved in the oral health care of children with special health care needs, but the pediatrician and others involved in the child's health care also can play an important role. These professionals must work together. Finding willing and qualified dental practitioners to treat children with special health care needs, and paying for the services needed, are amongst the largest barriers families face.

*The child's oral health-promoting behaviors are affected by the child, the parent, the practitioner, and the service system.*

*The preventive, restorative, and emergency dental care needed by all children are also needed by this special population. In addition, more intensive care and other rehabilitative services may be needed.*

- The way in which the service system promotes oral health also affects the oral health care of children with special health care needs. Many private insurance companies do not provide sufficient coverage or include exceptions for special services or equipment needed by children with special health care needs. Families receiving public assistance may face limitations in coverage and problems finding available, skilled providers who will accept them.

The preventive, restorative, and emergency dental care needed by all children are also needed by this special population. More intensive care in these areas and other rehabilitative services may also be needed. For example, children who have difficulty practicing or cooperating with home care, or who are more susceptible to dental decay or periodontal disease, may benefit from more frequent, intense preventive care. They may need more restorative and emergency care. Other children with congenitally atypical or missing oral structures or function may be in need of rehabilitative care that typical children usually do not need; for example, children with ectodermal dysplasia may be missing teeth and require implants, which are costly and not often covered by insurance.

To develop plans to identify, treat, and pay for the specific dental needs of these children, it is first necessary to understand these children and their dental needs. Parents, practitioners, and service system regulators must then be educated about these needs. Preventive care must be addressed as early as possible, before the problems start. Parents should be educated on the preventive dental needs of their child by pediatricians and other health professionals who see the child before they ever reach dental practitioners. Not only do dental practitioners need to be educated on treating the dental issues of children with special conditions, but other health practitioners also need to be educated about the dental issues that these children may face.

(This paper is presented in its entirety as an attachment to this report.)

## Nutrition and Oral Health

**Mary P. Faine, MS**

Nutritional status and oral health are closely associated in children with neurodevelopmental disabilities, those with craniofacial malformations, metabolic disorders, or those born prematurely. Special needs children are especially susceptible to oral infections. Feeding problems of special needs children may affect oral health. Developmental dental enamel defects may result from a nutritional insult during pregnancy or early childhood. Daily use of multiple medications can compromise oral and nutritional status. Diet plays a pivotal role in the development of dental caries; children with neurological impairments such as cerebral palsy often require prolonged feeding times to obtain adequate calories. Other nutritional issues that affect the risk of oral disease in children with developmental disabilities are described below.

### **Development of oral structures**

There is emerging evidence that early malnutrition affects tooth development and eruption and results in increased dental caries in the primary teeth. Enamel defects have been reported in a high number of pre-term infants with very low birthweights ( $\leq 1,500$  gm). Craniofacial malformations appear to have many characteristics in common with neural tube defects, the risk of which is reduced by folic acid supplementation during the first months of pregnancy. There is increasing evidence that folate supplementation prior to and during early pregnancy may be beneficial in preventing orofacial clefts. Children with cleft lip/palate disorders have more decayed, missing, and filled teeth than children without these conditions.

### **Gastroesophageal reflux**

Gastroesophageal reflux is very common in children with cerebral palsy and severe mental retardation. Erosion of primary and permanent teeth results from regurgitation of the acidic gastric contents into the mouth. Symptoms in children include: difficulty in sleeping, feeding problems, general irritability, bronchitis, laryngitis, asthma, and anemia. Medications can be prescribed to reduce the risk of this condition. Systemic and topical fluorides are recommended to prevent enamel erosion.

### **Dental caries**

Dental caries is the most common disease of childhood, but comprehensive oral health surveys to determine the rates of decay in children with neurodevelopmental disabilities are lacking. Caries rates are thought to

*Higher caries rates are seen in children with oromotor dysfunction, unhealthy dietary patterns, poor oral hygiene, or those who use a sucrose-based medication on a daily basis.*

be similar for children with developmental disabilities and healthy children if they have healthy diets and good oral hygiene. Many of these children are less mobile and depend on their caregivers to provide snacks. Higher caries rates are seen in children with oromotor dysfunction, unhealthy dietary patterns, poor oral hygiene, or those who use a sucrose-based medication on a daily basis.

### **Early childhood caries**

Early childhood caries (ECC) occurs in 5–10% of children 2 to 3 years old. The prevalence of ECC in children with special health care needs is not documented. Because the nursing bottle is often used for an extended period of time by those with developmental disabilities such as Down syndrome, ECC rates may be elevated. Early childhood caries is associated with inappropriate feeding of sweet liquids, formula, cow's milk, fruit juices, or fruit drinks in a bottle, especially at bedtime.

### **Use of medications**

Long-term medication use presents several challenges to a child's oral health. Cough preparations may be formulated with syrups containing high concentrations of glucose, high fructose corn syrup, fructose, or sucrose to improve palatability. These medications, if taken at naptime or bedtime, can be particularly harmful to teeth. When compared with their healthy siblings, chronically ill children taking long-term liquid oral medications had significantly more decay in their anterior teeth.

Further studies are needed to document the food choices and eating patterns of children with developmental disabilities that affect their oral health. The findings of these studies would be useful in developing nutrition education materials for clinicians and parents.

(This paper is presented in its entirety as an attachment to this report.)

# Oral-motor Dysfunction

**Peter Blasco, MD, FAAP**

Oral-motor function is considered an integral part of oral health. Oral-motor dysfunction can result in a spectrum of oral health problems, some but not all affecting the teeth. This paper outlines the spectrum of oral-motor dysfunctions, focusing mainly on cerebral palsy.

## **Structure and function**

Effective oral functioning—chewing, swallowing, speaking, etc.—is dependent upon the structural integrity of oral structures and on the functional integrity of neural mechanisms serving the face, mouth, pharynx, and to a lesser extent, respiratory control. Varying degrees of oral dysfunction will ensue as a consequence of loss of extra-oral architecture, intra-oral structural problems, central nervous system (CNS) motor encephalopathies, peripheral neuromuscular system disorders, joint or soft tissue restrictive diseases, and severe intellectual limitations or psychoemotional disorders. The oral-motor consequences of these disorders can be viewed as a continuum of oral performance impairments, which include speech problems (articulation and phonation), feeding and swallowing difficulty, drooling, upper respiratory congestion, and pulmonary aspiration.

## **Drooling and its treatment**

Saliva serves a number of very important functions, including protecting the teeth from decay and the gingival tissues from inflammation and periodontal disease. About 10% of children with cerebral palsy (CP) are believed to have drooling problems significant enough to interfere with daily social and practical functions. A much smaller population of individuals exists who have lost the structural integrity of the jaw and/or lips as a result of trauma or oropharyngeal tumors with resultant chronic drooling. Inadequate swallowing and lip closure are the critical factors causing children to drool. The term “posterior drooling” has been applied to the situation in which oral secretions are not lost externally but pool in the hypopharynx where they should normally stimulate a swallow reflex. In the absence of adequate swallowing, they produce a clinically more serious posterior spill through the faucial isthmus into the pharynx, which results in congested breathing, coughing, gagging, vomiting, and at times aspiration into the trachea. Although severe oral-motor dysfunction is a factor in posterior drooling, there is likely a significant pharyngeal sensory deficit and/or a central disruption of the sensorimotor connections, interfering with reflex swallowing.

*Effective oral functioning is dependent on the structural integrity of oral structures, the functional integrity of neural mechanisms serving the face, mouth, and pharynx, and on respiratory control.*

*Oromotor dysfunction increases risk of gastroesophageal reflux, aspiration, and abnormal orofacial muscle tone. These can lead to enamel erosion, respiratory infection, and malocclusion.*

Many modalities—various hands-on therapies, medications to dry secretions, surgery to eliminate gland function, oral appliances to stimulate swallow, even radiation—have been proposed, often in combination, to treat drooling. No one option is universally successful.

### **Effects on teeth**

Oral/dental health problems can cause problems in tissues in proximity to or connected to the mouth by direct extension (for example, respiratory tract infection or obstruction) and can also be the source of systemic difficulties (for example, endocarditis). In children with CP, dental health is negatively affected indirectly by virtue of the many associated deficits—for example, seizures. By virtue of trauma, either self-inflicted (biting) or the consequence of a fall, the lips, tongue, buccal mucosa, or teeth can be badly damaged.

The mouth is connected to the rest of the gastrointestinal tract, and more distant gastrointestinal problems can influence teeth (for example, gastroesophageal reflux [GER]). Children with central nervous system disorders, especially severe CP and mental retardation, are at markedly higher risk to have GER than the general pediatric population. Reflux of the acidic contents of the stomach into the mouth causes dental erosions. Because of abnormal orofacial muscle tone, children with CP are also more prone to malocclusion. Surgical treatment, because of its potential to produce irreversible and complete loss of saliva, has received some limited scrutiny in terms of dental outcomes. Several studies have shown an increased caries risk (even in the absence of xerostomia) for children with CP following surgery to control drooling.

Although there is considerable literature available on some of these issues, the great majority of the scientific evidence generated is low on the rules of evidence scale. There remains enormous room for high quality research in all topics touched on in this overview.

(This paper is presented in its entirety as an attachment to this report.)

# Oral Health and Speech

**Judith Trost-Cardamone, PhD**

This paper provides an overview of the impact of craniofacial anomalies on speech. It also proposes training and research initiatives that would lay some groundwork for the multifaceted task of improving the oral health of children with craniofacial anomalies and other special health care needs.

## **Training initiatives**

1. Dental and medical specialists should be better informed about speech development, disorders and treatment, in general, and craniofacial and related developmental speech disorders in particular. This includes exposure to craniofacial team care and specialists. To this end, a course of study on speech pathology should be a part of the curriculum in all dental and medical schools.
2. Speech-language pathologists should be better informed about oral health, nutrition, and pediatric medicine, especially developmental pediatrics. Coursework on these topics should be a part of the graduate curriculum in communication sciences and disorders.
3. Dental, medical, and speech-language pathology students should be better informed about federal health care legislation and associated health care policy.
4. Interdisciplinary and related health care policy coursework for dental, medical, and speech-language pathology students could be delivered through traditional onsite scheduled lectures and observational experiences, via online distance education, or a combination of both.
5. Professional specialty organizations should include interdisciplinary presentations at national and regional meetings. Health care professionals should pursue continuing education outside of their specialty areas.
6. Training grants should be developed to promote trans-disciplinary knowledge and skills. For example, speech-language pathologists (SLPs) could be trained to do oral health screenings as a part of the routine orofacial examination. The majority of SLPs are employed in the public schools.

*Dental and medical specialists should be better informed about speech development, disorders and treatment, in general, and craniofacial and developmental speech disorders in particular.*

*Speech-language pathologists could be trained to do oral health screenings as a part of routine orofacial exams.*

## Research initiatives

1. Obtain basic outcome data on team care for children with non-syndromic cleft palate (with or without cleft lip). Multi-center research should study:
  - surgical outcomes of palate surgery as measured by velopharyngeal speech function
  - surgical outcomes in facial esthetics
  - orthodontic/orthognathic outcomes as measured by speech articulation
  - quality of life outcomes
2. Obtain basic data on cost of team-based craniofacial care by conducting a study on the economics of team care, in partnership with major insurance providers.
3. Obtain speech data on the effects of early intervention. To accomplish this, prospective, longitudinal multi-center studies on (interim) speech outcomes are needed.
4. Establish a uniform approach to the assessment of craniofacial speech outcomes. This initiative involves three sequential tasks: conducting a survey to collect data on current assessment practices; using the survey results to develop a recommended protocol; and convening a group of craniofacial speech pathologists to establish consensus on a “standard” protocol.
5. Obtain data on the effects of traditional articulation therapy on the correction of compensatory misarticulations. It would conduct multiple controlled small group studies using SLPs experienced in craniofacial speech disorders.
6. Establish the efficacy of instrumental biofeedback approaches to speech remediation in cleft palate. The first part of this initiative would involve conducting multiple small group studies on the efficacy of electropalatography in the correction of cleft plate compensatory misarticulations. The second part would involve conducting multiple small group studies on the efficacy of videonasopharyngoscopy in correcting velopharyngeal closure inadequacy in mild/marginal cases of velopharyngeal inadequacy.

(This paper is presented in its entirety as an attachment to this report.)

## Prematurity and Oral Health

**Rocio Beatriz Quinonez, DMD, MS, FRCDC**

Insights from the field of periodontal medicine suggest that periodontal infections contribute to the morbidity and mortality of individuals with certain systemic conditions by acting as an effect modifier or an independent risk factor. The association between maternal periodontal disease and prematurity in particular, is a relevant health care issue because pre-term, low-birthweight deliveries represent 10% of all U.S. births and account for two-thirds of all infant mortality. These levels have remained stagnant during the past 25 years, despite intensive research, tremendous prenatal clinical care efforts, and high financial costs, that are estimated at \$5.5 billion annually in intensive care unit costs alone. In addition, pre-term, low-birthweight births (particularly of babies <1,500g) often cause long-term disabilities such as respiratory disease, cerebral palsy, and other neurodevelopmental disabilities. The management of these conditions is costly and can alter the child's quality of life as well his/her family's quality of life.

In the past few years, there has been increasing evidence to suggest that infection may play a role in pre-term deliveries. Although the mechanisms are not well understood, it is thought that either the host, fetus, and/or mother signal the onset of labor to escape a hostile environment. In cases of vaginal infection, bacteria or their products ascend to the maternal-fetal compartment and induce an inflammatory response; cytokines then become capable of inducing conditions such as uterine contraction and cervical dilation, terminating in parturition. But there are many cases where inflamed membranes leading to prematurity are not associated with vaginal infection. There is now evidence that remote infections may cause prematurity. So the question then becomes, could bacteria from a periodontal infection be associated with pre-term, low-birthweight births?

Periodontal disease is also a type of infection. It represents a chronic inflammatory response to subgingival bacterial infection, resulting in loss of ligament, bone, and tooth. It affects 7-15% of the adult population, depending on definition of severity. In the late 1980s and 1990s, animal studies showed that experimental periodontitis as well as localized subcutaneous infections with *Phorphyromonas gingivalis* could significantly retard fetal growth. These findings led to cross-sectional clinical studies at the University of North Carolina suggesting that 18% of low birthweight births may be attributable to periodontal disease. Although the studies showed linkage but not a causal relationship, the findings generated considerable publicity and led to a National Institute

*Periodontal disease may be a modifiable risk factor for premature births when compared with other factors such as genetics and socioeconomic status.*

of Dental and Craniofacial Research financed study of the contribution of oral disease to pregnancy complications.

Currently, this study has 1,200 women enrolled, with a target goal of 1,500. Preliminary findings seem to confirm earlier studies showing that mothers who have pre-term, low-birthweight babies have more severe periodontal disease prior to delivery. Worsening of periodontal disease during pregnancy appears to present greater risk for pre-term, low-birthweight births.

Maternal periodontal infection can also provide a systemic challenge to the fetus *in utero*.

Researchers have examined fetal cord blood and found that it contains IgM specific to periodontal pathogens. It is known that IgM does not cross the placental membrane, thus providing direct evidence that periodontal pathogens themselves or other products have crossed the membrane to reach the fetus, providing a systemic challenge to the fetus *in utero*.

Other studies seem to confirm these findings. A study at the University of Alabama has shown that in a group of more than 1,300 women examined at 21-24 weeks during pregnancy, there were a higher number of premature deliveries among women with periodontal disease. Similarly, a study from Santiago, Chile, suggests that periodontal therapy has a beneficial effect on reducing rates of prematurity in more than 800 women.

Periodontal disease is a modifiable risk factor when compared with other factors such as genetics and socioeconomic status. These data may lead to change and expansion of treatment objectives and provide new opportunities for diagnostics. Furthermore, they suggest that dental education will need to move more into the mainstream of medicine.

# Medically Complex Patients

**Bryan J. Williams, DDS, MSD**

In health system planning, the dental health needs of medically complex children may often be overlooked. At certain times in their medical conditions, untreated dental disease can result in major compromises in care and can be life-threatening.

Dental disease rates vary widely in the special needs child population. In general, the dental disease rate for children with cardiac conditions, hemotologic conditions, or cancers will mimic or be slightly higher than the general child population, but with the potential for severe systemic consequences. For example, if a child with active dental disease requires complex cardiac surgery, a delay in surgery due to the presence of dental infection can be life-threatening. Similarly, if a child develops leukemia, chemotherapy may not be initiated until active dental disease is managed. As chemotherapy and/or radiation therapy progresses, the risk for dental disease increases due to decreases in salivary flow, increasing difficulty in maintaining oral hygiene, and alterations in the immune system. Oral side effects of treatment such as mucositis can be very significant and require dental management. The dental disease rate for children with cleft palate and craniofacial anomalies is higher than the general child population due to feeding needs, the frequency of enamel defects, the difficulty of oral hygiene measures with mal-positioned teeth, and the interaction of poor self-image on the child's oral self-care.

## **Important issues for the dentist**

There are two primary issues the dentist must consider in the management of a child with cardiac or hematology-oncology problems or craniofacial anomalies. The first issue is assessing the impact of the child's medical condition on the dentist's ability to provide appropriate dental treatment. The second issue is understanding the impact of dental and oral disease and the provision of dental treatment on the child's overall medical condition. The dentist may also be thrust into the somewhat foreign role of case coordinator for a child with a complex medical problem, spending significant amounts of time communicating with the medical team and planning the most appropriate treatment approach and timing. Appointment attendance can be problematic.

*In health system planning, the dental health needs of medically complex children may often be overlooked.*

*The medically complex child patient presents a challenge that requires a significant level of expertise on the dentist's part. Dental students receive very limited exposure to these children.*

### **Service implications**

Children who have cardiac or hematological problems or craniofacial anomalies must have access to timely and skilled dental care. The most complex of these patients will require treatment in a dental service that is an integral part of a tertiary care pediatric medical center. The dental services in tertiary care pediatric medical centers are currently overwhelmed with patient care demands and inadequately supported. These institutions must realize that the combination of treatment complexity and current reimbursement patterns for these patients precludes hope of profitability.

Children who have lower grade cardiac, hematologic, or craniofacial conditions can be safely treated in the community by practitioners with appropriate skill levels and interest.

### **Training implications**

The medically complex child patient presents a challenge that requires a significant level of expertise on the dentist's part. Dental students receive very limited exposure to these children. Consequently, the general dentist graduates with limited skills in the management of these children. General dentists would be better equipped to manage these patients if appropriate continuing education opportunities were made available and more emphasis on treatment of special populations included in undergraduate dental education. The dental care of these children should be an integral part of pediatric dental specialty training. These specialty training programs have varying amounts of exposure to these patients; hospital-based programs tend to offer the most experience.

### **Research implications**

Clinically based research opportunities abound, but the limitations of resources in clinical centers make this research difficult. There is much to gain in research for this segment of the special needs child population. A national focus on such research will reap tangible benefits for these children and society, and may also illuminate important oral-systemic health linkages.

## Access to Dental Care for Group Home Residents in Iowa

**Jodi A. McGrady, DMD, MS, Michael J. Kanellis, DDS, MS, John J. Warren, DDS, MS  
Steven M. Levy, DDS, MPH**

One area of the deinstitutionalization process that has had only limited success is the provision of oral health care services for these individuals within the community. Many studies have shown that the oral health of individuals with developmental disabilities, although dependent upon many factors, is generally poorer than the oral health of the general population. For example, individuals with more severe disabilities may rely fully upon other individuals for oral hygiene assistance, which may not always be provided routinely. At the other extreme, residents requiring only minimal supervision may have poor oral hygiene habits and poor food selection, resulting in a decline in oral health, even though these individuals have greater functional abilities.

Factors that interfere with the receipt of dental treatment by this population include lack of dentists' training, significant problems in financing dental care, structural barriers in many dental offices, the inability of patients to cooperate with dental treatment, and complex issues of parental consent and legal guardianship. To improve the access to oral health care for people with developmental disabilities, a comprehensive understanding of the barriers to care is necessary.

### Methods

For this study, a 41-item survey was conducted by telephone with administrators from group homes in Iowa. Perceived access to dental care was assessed by asking administrators to respond to the question, "How would you rate your ability to get dental care for clients of your group home(s)?" Information was also collected on multiple group home factors, client factors, and dentist factors that were believed to be related to access. Two broad types of group home facilities were surveyed: Intermediate Care Facilities for the Mentally Retarded (ICF/MRs) and Residential Care Facilities for the Mentally Retarded (RCF/MRs).

*Factors that interfere with the receipt of dental treatment by this population include lack of dentists' training, problems in financing dental care, structural barriers in many dental offices, the inability of patients to cooperate with dental treatment, and issues of consent and legal guardianship.*

## **Results**

Participation rates in the survey were high, with 120 group home administrators providing information for 318 group homes (91.6%). The 318 homes with responses housed 3,150 individuals with developmental disabilities. Survey responses indicated that 95.5% of group home residents received Medicaid benefits. For the 238 group homes that reported the name and distance to the office of their dentist of record, the mean distance was 8.8 miles (range 0.5 to 70 miles). Most clients were treated by general dentists (79.8% of homes), while 48 (20.2%) had pediatric dentists as their dentist of record.

Overall, respondents expressed satisfaction with their ability to get dental care for their clients; 85.2% indicated their ability to get dental care for their clients was "good," "very good," or "excellent." Only 14.8% indicated their ability to get dental care for their clients was either "fair" or "poor." This study found a statistically significant difference between the ICF/MR and RCF/MR homes in their ability to access dental care. The primary explanation for this difference is that RCF/MR residents are generally of much higher function. This finding suggests that the severity of the disability can influence access to dental care.

## **Conclusions**

This study found that problems with perceived access to dental care for the population with developmental disabilities living in group homes were relatively uncommon. Group homes reporting poor access to dental care were more likely to report that: 1) local dentists were uncomfortable treating patients with developmental disabilities; 2) local dentists would not accept new Medicaid-enrolled patients; 3) dental offices were too far away; and 4) dental offices were not wheelchair accessible. Group home representatives felt the primary problem in access was dentists' refusal to accept Medicaid patients. Many respondents perceived the dentists as being uncomfortable or even fearful of their clients and that physicians as well as dentists were not confident in treating them.

(This paper is presented in its entirety as an attachment to this report.)

# Access to Care: A Clinical Perspective

**F. Thomas McIver, DDS, MS**

Beginning in the late 1960s, children and adults have been gradually but steadily moved out of large state institutions for people with disabilities. Now all but a relatively few children and adults with neurodevelopmental disabilities and other special care health needs are out of institutions and are seeking oral health care through community resources. State and community planners expected the health care of these people to be integrated into the existing community health resources. In respect to oral health services, this integration has been severely limited in most communities.

If all oral health care factors had developed in an optimum way, the following scenario would illustrate the standard in oral health care. A mother and father would bring their 10-month-old Down syndrome son to a dental office for his first appointment, having received prenatal counseling to do this. The child would be examined by a well-trained dental team. The family would depart with knowledge of how to promote good oral health and a determination that their child will have good oral health. They will return for regular preventive care. Through the months and years of returning for preventive care, the child will learn to be a competent dental patient who actively cooperates with prescribed dental procedures. Meanwhile the dental team has been adequately compensated for providing oral care for this person with Down syndrome.

What are the barriers to getting this level of care? They can be divided into five key areas: the primary medical care system, which frequently fails to include oral health in the overall plan for the child; the parents, who may inadvertently promote oral disease or avoidance of dental care; the child, whose needs range from routine treatment to use of a general anesthetic; the dentist, who may not treat children with special needs for a variety of reasons; and the payment system, which rarely provides for comprehensive dental care for these children, many of whom are covered by Medicaid.

To deal with these many issues a broad approach is required. Every state and community has its unique set of strengths and resources to address these barriers. However, any effort to improve access to care requires an

*Now all but a relatively few children and adults with neurodevelopmental disabilities and other special care health needs are out of institutions and are seeking oral health care through community resources.*

*Along with the development of the dental work force is the need to enhance oral health training of physicians and other health care professionals who are likely to interact with children with special needs.*

adequate dental work force trained to meet the preventive and therapeutic needs of this population. In addition, a profession-wide effort may be needed to bring dentists to the point of recognizing a responsibility to provide dental care to Medicaid patients, especially those with special needs.

Along with development of the dental work force is the need to enhance oral health training of primary care physicians and other health care professionals who are likely to be interacting with children with special needs. There are opportunities for collaboration between university and regional dental clinics for people with disabilities. Mobile unit programs send dental teams to facilities where there are special needs patients. Some dentists donate their services, such as through the Foundation for Dentistry for the Handicapped. The closing and downsizing of institutions for people with disabilities have caused the loss of some skilled and knowledgeable dental staff. But in some areas, this valuable resource has been retained to support continued provision of care for patients through outpatient services, or providers have become involved in community-based training efforts.

Optimum oral health for children and adults with special needs depends in part on health care providers outside of dentistry. Physicians, nurses, and group home personnel, for example, must know how to prevent common oral diseases and give appropriate priority to preventive measures. Health care providers outside of dentistry have more frequent contact with people with special needs, making it possible for them to monitor oral health and assure they are receiving appropriate dental care. Dental schools and other training programs must address the workforce deficiency of providers trained to work with this population. Creating a means of paying for care that recognizes the important differences in special needs people is crucial to improving access to care for this group. Studying successful programs and sharing knowledge should also be a priority.

(This paper is presented in its entirety as an attachment to this report.)

# 10. Appendices

# Conference Agenda

## Promoting Oral Health of Children with Neurodevelopmental Disabilities and Other Special Health Needs: A Meeting to Develop Training and Research Agendas

May 4 and 5, 2001

Center on Human Development and Disability  
CHDD Auditorium, CD150  
University of Washington

**Friday, May 4, 2001**

**Morning**

**7:30 Continental Breakfast and Registration**

**8:00 Welcomes and Introductions**

John F. McLaughlin, MD, University of Washington and CHDD

M. Ann Drum, DDS, MPH, Maternal and Child Health Bureau, HRSA

Timothy DeRouen, PhD, Center for Comprehensive Oral Health Research, University of Washington

John Liu, DDS, American Academy of Pediatric Dentistry

**Session I: Setting the Stage**

**8:15 - 8:30 Overview and Charge**

Wendy Mouradian, MD, MS, University of Washington

National Institute of Dental and Craniofacial Research, NIH

**8:30 - 8:50 Oral Health and the Future: Implications for Children with Neurodevelopmental Disabilities/  
Children with Special Health Care Needs.**

Harold Slavkin, DDS, University of Southern California

**8:50 - 9:10 Conceptual Framework for Health Promotion**

Ruth Nowjack-Raymer, MPH, PhD

National Institute of Dental and Craniofacial Research, NIH

**9:10 - 9:30 Conceptual Framework for Disability**

Ralph Nitkin, PhD, National Center on Medical Rehabilitation Research, National Institute of Child Health and Human Development, NIH

**9:20 - 9:45 What's In A Face: Neurodevelopmental Disorders**

Sterling Clarren, MD, Children's Hospital and Regional Medical Center, and University of Washington

**9:45 - 10:00 Questions**

**10:00 - 10:15 Break**

**Session II: Oral Health and Special Children**

**10: 15 Panel: Oral Health in Children with Neurodevelopmental Disorders and other CSHCN**

Moderators:

Peter Domoto, DDS, MPH, University of Washington

Arthur Nowak, DMD, University of Iowa

**10:15 - 10:30 Oral Biology Made Simple**

Joel Berg, DDS, Philips Oral Healthcare

**10:30 - 10:55 Oral Health in Children With Neurodevelopmental Disorders and Other CSHCN**

Arthur Nowak, DMD, University of Iowa

**10:55 - 11:10 Special Olympics, Special Smiles: Data Collection in Special Populations**

Mark Wagner, DMD, Special Olympics, Inc.

**11:10 - 11:25 Questions**

**11:30 Panel: Oral Health Promotion: Defining and Delivering the Goods**

Moderator:

Ruth Nowjack-Raymer, MPH, PhD, National Institute of Dental and Craniofacial Research, NIH

**11:30 - 11:45 Parents as Partners in Health Promotion for CSHCN**

Betsy Anderson, Family Voices, Boston

**11:45 – 11:55 Obstacles to Promoting Oral Health: A Parent Study**

Susan Cheffetz, DMD, MEd, University of Southern California

**11:55 - 12:15 Evidence-based Approaches**

James Crall, DDS, ScD, HRSA/MCHB National Oral Health Policy Center, Columbia University

**12:15 Working Lunch - Work Group Discussions 1**

Key training, research, and service and policy implications related to:

1. Families; Oral health promotion
2. Oral health of children with neurodevelopmental disabilities and other/CSHCN
3. Data collection and evidence based-approaches
4. Policy implications (of above)

# Friday

# Afternoon

## Plenary 1:45 - 2:15 Presentation of Work Group Discussions

Moderator: John McLaughlin, MD

CHDD Auditorium

## Session III: Interdisciplinary Issues

Moderator: Peter Blasco, MD, Oregon Institute on Disability and Development, Oregon Health Sciences University

### 2:15 - 2:25 The Spectrum of Oral-Motor Dysfunction

Peter Blasco, MD, Oregon Institute on Disability and Development

### 2:25 - 2:50 Oral Health and Speech: The Impact of Craniofacial Anomalies

Judith Trost-Cardamone, PhD, California State University at Northridge

### 2:50 - 3:30 Nutrition Issues in Oral Health

Mary Faine, MS, RD, University of Washington

### 3:30 - 3:40 Questions

### 3:40 - 5:00 Break and Work Group Discussions

Key training, research, service, and policy implications related to:

1. Oral-motor dysfunction and speech
2. Nutrition
3. Policy implications (of above)

### 5:00 - 5:30 Presentation of Work Group Discussions

Robert Jacobs, MD, Center for Child Development and Developmental Disabilities, University of Southern California, Childrens Hospital Los Angeles

### 5:30 Afternoon Session Ends

### 7:00 Dinner and Evening Presentations (University of Washington Faculty Club)

Developmental and Behavioral Aspects of Health Promotion

Norman Braveman, PhD, National Institute of Dental and Craniofacial Research

Susan Cheffetz, DMD, University of California, Los Angeles

**Saturday, May 5, 2001**

**Morning**

**8:00 Continental Breakfast**

**Session I: Oral-systemic Health Interactions**

**8:30 Oral-Systemic Health Interactions and CSHCN**

Moderator: Louise Iwaishi, MD  
Center for Disabilities Studies, University of Hawaii

**8:30 - 8:50 Maternal Oral Disease and Low Birthweight**

Rocio Quinonez, DMD, MS, University of North Carolina

**8:50 - 9:10 Craniofacial, Cardiac, Hematology/Oncology Issues**

Bryan Williams, DDS, Children's Hospital and Regional Medical Center

**9:10 - 9:15 Questions**

**SESSION II: Access**

**9:15 - 9:45 Access to Oral Health Care for Special Children**

Moderators:

Olson Huff, MD, Mission St. Joseph's Graham Children's Health Center, NC

Peter Domoto, DDS, MPH, University of Washington

**9:15 - 9:30 Insights from Health Services Research**

Michael Kanellis, DDS, MS, University of Iowa

**9:30 - 9:45 Clinical Insights**

Thomas McIver, DDS, University of North Carolina

**9:45 - 10:00 Questions**

**10:00 Break**

**SESSION III: Training**

**10:15 - 11:30 Panel: Oral Health Training for All Professionals and Families: The Interdisciplinary Imperative**

Moderators:

Sharon Turner, DDS, JD, School of Dentistry,  
Oregon Health Sciences University

Tina Tamai, RDH, MPH, JD, University of Hawaii

Panelists:

John McLaughlin, MD, Washington

Peter Blasco, MD, Oregon

Robert Jacobs, MD, California

Louise Iwaishi, MD, Hawaii

Michael Kanellis, DDS, MS, Iowa

Thomas McIver, DDS, North Carolina

Parent representative

**11:30 - 11:45 View from the Dean's Office**

Harold Slavkin, DDS, University of Southern California School of Dentistry

**11:45 Lunch and Work Group Discussions**

Key training, research, service, and policy implications related to:

1. Oral-systemic health interactions
2. Behavioral and developmental issues
3. Access
4. Policy implications

**Saturday**

**Afternoon**

**1:15 - 4:15 Planning for the Future**

Moderators:

John McLaughlin, MD

Wendy Mouradian, MD, MS

**1:15 - 1:45 Presentation of Work Group Discussions**

**1:45 - 2:15 Final Charge for Work Groups: Training and Research Paradigms**

Ann Drum, DDS, MPH and Norman Braveman, PhD

**2:15 - 3:30 Break and Work Groups**

**3:30 - 4:15 Report Back and Next Steps: wrap-up**

Arthur Nowak, DMD; Wendy Mouradian, MD, MS; John McLaughlin, MD

**4:15 Adjourn**

# Faculty and Attendees

Betsy Anderson, Family Voices, Federation for Children with Special Needs, Boston

Joel H. Berg, DDS, MS, Vice President Clinical Affairs, Philips Oral Healthcare, Snoqualmie, WA

Peter Blasco, MD Associate Professor of Pediatrics, Oregon Health and Science University and Director, LEND training program

Norman S. Braveman, PhD, Associate Director for Clinical, Behavioral, and Health Promotion Research, National Institute of Dental and Craniofacial Research

Sterling K. Clarren, MD, Director of Inpatient Medical Services, Children's Hospital Regional Medical Center and Washington State FAS Diagnostic and Prevention Network

James J. Crall, DDS, ScD, Director, National Oral Health Policy Center, Columbia University College of Dentistry and Oral Surgery

Susan Cheffetz, DMD, MEd, doctoral candidate, University of California, Los Angeles

Timothy A. DeRouen, PhD, Chair, Dental Public Health Sciences, Director, Comprehensive Center for Oral Health Research, University of Washington.

Peter Domoto, DDS, MPH, Professor and Chair, Department of Pediatric Dentistry, University of Washington School of Dentistry.

M. Ann Drum, DDS, MPH, Director of the Division of Research, Training, and Education for the federal Maternal and Child Health Bureau.

Mary P. Faine, MS, RD, Associate Professor and Director of Nutrition Education, University of Washington School of Dentistry.

Kathleen Holt, JD, MBA, parent representative

Louise Kido Iwaishi, MD, Director, Division of Community Pediatrics, University of Hawaii, and Director, LEND training program.

Robert Jacobs, MD, MPH, Professor of Pediatrics and Chief, General Pediatrics, Childrens Hospital of Los Angeles and Director, LEND training program.

Michael Kanellis, DDS, MS, Professor and Chair, Pediatric Dentistry, University of Iowa, Center for Leadership Education in Pediatric Dentistry.

F. Thomas McIver, DDS, MS, Professor of Pediatric Dentistry, University of North Carolina at Chapel Hill.

John F. McLaughlin, MD, Professor of Pediatrics at the University of Washington and Director, LEND training program

Wendy Mouradian, MD, MS, Associate Clinical Professor of Pediatrics, Pediatric Dentistry and Health Services, University of Washington

Ralph Nitkin, PhD, National Center for Mental Retardation Research, National Institute for Child Health and Human Development, NIH

Arthur J. Nowak, DMD, Professor Emeritus, Pediatric Dentistry and Pediatrics, Colleges of Dentistry and Medicine, University of Iowa.

Ruth Nowjack-Raymer, RDH, MPH, PhD, Office of Science Policy and Analysis, National Institute of Dental and Craniofacial Research, NIH

Rocio Beatriz Quinonez, DMD, MS, Fellow, NIH, and Robert Wood Johnson Clinical Scholar, University of North Carolina at Chapel Hill

Harold C. Slavkin, DDS, Dean, University of Southern California School of Dentistry

Tina Tamai, RDH, MPH, JD, University of Hawaii, Dental Hygiene faculty, LEND training program

Judith Trost-Cardamone, PhD, CCC-Slp, Professor of Communication Disorders and Sciences, California State University, Northridge

Sharon P. Turner, DDS, JD, Dean, Oregon Health and Science University School of Dentistry

Mark Wagner, DMD, Global Director of Health and Research Initiatives, Special Olympics Inc., Washington, D.C.

Bryan J. Williams, DDS, MSD, MEd, Director, Department of Dental Medicine, Children's Hospital and Regional Medical Center, Seattle

## Other Conference Attendees

Daryl Anderson, PhD, Oregon Health and Science University

Marion Taylor Baer, PhD, RD, University of Southern California

Krista Baier, DDS, University of Washington

Phyllis L. Beemsterboer, RDH, MS, EdD, Oregon Health and Science University

Michelle Bell, MS, MPH, PhD, University of Washington

Shamsi Bhanji, DDS, University of Washington

Janet H. Brockman, MS, CCC-Sp, Oregon Health and Science University, Oregon Services for Children with Special Health Needs, Title V

Robert E. Buda, DDS, Tukwila, WA

Diana Cantrell, RN, University of Washington

Maria Caruncho, MD, University of Washington

Mae M. Chin, RDH, University of Washington

Ginny English, Healthy Mothers, Healthy Babies of Washington

Chris Feudtner, MD, MPH, PhD, University of Washington

Jan Fleming, MN, Office for Children with Special Health Care Needs, Washington State Department of Health (Title V)

Christine Forsch, RDH, Nevada State Health Division, Title V

Dale C. Garell, MD, University of Southern California

Glenn Govin, DDS, University of Washington

Melia Hayashi, RN, University of Hawaii, LEND program

Patricia Heu, MD, MPH, Hawaii Dept of Health, Chief, Title V Children with Special Needs Branch

Katrina Holt, RD, MPH, Georgetown University

Betsy Howe, National Foundation for Ectodermal Dysplasias

Donald Huebener, DDS, MS, Washington University, St. Louis

Olson Huff, MD, Graham Children's Health Center, Asheville, NC

Ellen Hunt-Landry, Family Voices

Joseph Jedrychowski, DDS, University of Southern California

Stephanie Roemer Knott, MD, Children's Hospital and Regional Medical Center, Seattle

Peter Lax, DMD, Oregon Health and Science University

Penelope Leggott, DDS, MS, University of Washington

Sherry Lemon, MS, RDH, Oregon Health and Science University

Charlotte Lewis RD, MD, MPH, University of Washington

John R. Liu, DDS, American Academy of Pediatric Dentistry

Don Lollar, PhD, Centers for Disease Control and Prevention

Patrick Loughlin, DDS, University of Washington

Reginald Louie, DDS, MPH, HRSA Field Office, San Francisco

Heather Lynch, MD, Children's Hospital and Regional Medical Center, Seattle

Karen Martinek, Alaska Dept Health Social Services (Title V)

Randall Niederkohr, DDS, University of Southern California

Trish O'Grady, RDH, State of Wyoming Dept of Health

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Larry J. Platt, MD, MPH, California Dental Health Foundation

Jose Polido, DDS, MS, University of Southern California

Alice Porter, MSc, University of Washington

Susan Ramage, RN, MN, University of Washington

Nancy P. Reid, Washington State Dept of Health (Title V)

Susan Sandall, PhD, University of Washington

Barbara Sheller, DDS, Children's Hospital, Seattle

Jonathan D. Shenkin, DDS, MPH, National Institute of Dental and Craniofacial Research, NIH

Cynthia Shurtleff, MEd, American Academy of Pediatrics

Laura Sices, MD, University of Washington

Roy Simms, MD, American Academy of Pediatrics

Patricia McGill Smith, National Parent Network on Disabilities

Deborah Stauffer, RDH, EdD, University of Alaska

Lisa Steffian, MS, University of Wyoming

Ethel Steinmetz, MPA, Washington State Department of Health

Kevin John Stock, MA, American Academy of Pediatrics

David Sumikawa, DDS, MS, Honolulu, Hawaii

Charlene Sampley, University of Washington

Katherine Tokolste, MD, University of Washington

Susan L. Tengan, RDH, MS, Hawaii State Department of Health

Tari D. Topolski, PhD, University of Washington

Cristine M. Trahms, MS, RD, University of Washington

Christine Tweedy, DDS, MSD, University of Washington

Richard D. Udin, DDS, University of Southern California

Elizabeth Wehr, JD, George Washington University

Norma Wells, BS, RDH, MPH, University of Washington

Margaret A. West, MSW, PhD, HRSA Field Office, Seattle

Brad Whistler, DMD, Alaska Department of Health and Social Services

# Federal Training and Research Centers

Five types of federal training and/or research programs participated in this conference. They are:

## **Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities (LEND)**

Funded by a set-aside of the federal Maternal and Child Health Block Grant, the LEND programs work to improve the health of children who have or at are at risk of developing neurodevelopmental disabilities. The LEND programs offer leadership education and interdisciplinary training to child health professionals, encouraging improvements in the health services delivery systems for these children, and promoting innovative practice models and research programs. The federal program provides funds to 35 centers and encourages community-based partnerships and family-centered approaches to care. The LEND training projects collaborate with health, education, and social service agencies serving children with developmental disabilities.

## **Centers for Leadership in Pediatric Dentistry Education**

Two federally funded pediatric dentistry training projects, one at the University of Iowa and the other at the University of North Carolina at Chapel Hill, address gaps in training for dentists who would serve high-risk children, including children with special health care needs. The programs also serve as regional and national resources for other pediatric dentistry programs. They facilitate a national focus on leadership in areas such as postdoctoral training, teaching models, and continuing education, and trainees and faculty provide clinical services in a variety of settings.

## **University Centers of Excellence in Developmental Disabilities (UCEDDs), formerly University Affiliated Programs (UAPs)**

The mission of this national network of 61 centers (in every U.S. state and territory) is to serve as liaisons between institutions of higher learning and service delivery systems to increase the independence, productivity, and community integration of individuals with

developmental disabilities and their families. The centers engage in four broad tasks: conducting interdisciplinary training, promoting exemplary community service programs, providing technical assistance at all levels, and conducting research and dissemination activities. They are authorized through Section D of the 1990 Americans with Disabilities Act.

## **Mental Retardation and Developmental Disabilities Research Centers (MRRCs)**

The 14 MRRCs form the nation's major research effort for investigating the problems of mental retardation and other types of developmental disabilities. These centers of excellence are funded by competitive grants from the National Institute of Child Health and Human Development (NICHD), which is part of the National Institutes of Health (NIH). Core grants support both program coordination and central research facilities. Funds for specific research projects that use these core facilities come from the NICHD, other NIH Institutes, other federal agencies, state governments, and private foundations. The scope of the research programs conducted at the MRRCs encompasses every known major dimension of mental retardation. The MRRCs and the UCEDDs work closely together.

## **The National Center for Medical Rehabilitation Research (NCMRR)**

A component of the NICHD, the NCMRR supports research to enhance the functioning of people with disabilities in daily life. Its mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. A primary goal of the center is to bring the health-related problems of people with disabilities to the attention of the nation's best scientists in order to capitalize on the myriad advances occurring in the biological, behavioral, and engineering sciences. The majority of NCMRR funding goes to unsolicited investigator-initiated proposals that pass muster in the NIH peer-review system. In addition, NICHD supports an intramural research program in medical rehabilitation.

# Selected Recent Articles and Reports Highlighted at the Conference

## Bright Futures in Practice: Oral Health

Casamassimo P, ed. Arlington, VA: National Center for Education in Maternal and Child Health, 1996.

This report, part of the Bright Futures project of the federal Maternal and Child Health Bureau, addresses oral health needs of children and adolescents from birth to age 21 by presenting specific guidelines on current oral health disease promotion and disease prevention. It informs families and health professionals about oral development, dental caries, periodontal disease, malocclusion, effects of tobacco use, and injury. It supports efforts to identify services to improve oral health, develop and implement oral health programs, and train professionals and students. Bright Futures introduces the concepts of individualized risk assessment, emphasizes the contribution of dental and other health professionals and families, and stresses the importance of early oral health intervention for children, beginning with prenatal counseling. Copies are available through the Bright Futures web site: <http://www.brightfutures.org/oralhealth/about.html>

## Cleft Lip and Palate: Critical Elements of Care

Washington State Department of Health, Center for Children with Special Needs. Children's Hospital and Regional Medical Center, Seattle. First edition, November 1997, Revised March 2000.

This publication of the Critical Elements of Care series provides a framework for a consistent approach to management of children with cleft lip and palate, based on guidelines developed by an interdisciplinary team of health care providers and family members. The report explores the goals of treatment and important themes in achieving them. It provides a list of key interventions by age (prenatal to 21 years), which links interventions to specific problems such as feeding difficulties, family crises, and abnormal dental development. Among the interventions are medical diagnosis and genetic counseling, dental/orthodontic problems, recognition of school and psychosocial issues, feeding plans and instructions, and hearing and language assessments. The report lists standards of care created by the American Cleft Palate-Craniofacial Association and offers discussions about prenatal diagnosis, primary care, nursing and feeding issues, and plastic surgery. It concludes with a glossary. Available at:

<http://www.cshcn.org/resources/resources.htm#healtheducation>

## Disparities in Children's Oral Health and Access to Dental Care

Mouradian W, Wehr L, and Crall JJ. JAMA 2000; 284 (20): 2625-31.

This article explores the role of community, professional, and individual measures in preventing dental caries—the most common disease of childhood. Data show that children from low-income and minority families have poorer oral health outcomes, experience fewer dental visits, and receive fewer preventive sealants. Although the infectious nature of dental caries requires preventive oral health, only 1 of every 5 children covered by Medicaid receives the preventive oral care for which they are eligible. Many pediatricians lack critical knowledge to protect oral health. The authors' recommendations include financial incentives to prioritize Early and Periodic Screening, Diagnostic, and Treatment in Medicaid-financed dental services, managed care contract specifications for oral health services and, greater integration of oral health into overall health care in training, service, and policy.

## Health Status and Needs of Individuals with Mental Retardation

Horowitz SM, Kerker BD, Owens PL, Zigler E. Washington, DC. Special Olympics, Inc. March 2001.

This 2001 report from Special Olympics Inc. explores issues including prevalence of physical health conditions, mental health, ocular impairments, and access to health services. A chapter on dental health examines prevalence and health status across specific populations. Special Olympics routinely conducts oral health screenings at events and have examined these data in several studies. The organization reports that the oral health status of 6-8 year-olds is similar to that of the general population, but athletes 15 years and older have more dental disease. The report cites data that indicate that a greater share of children with mental retardation are falling short of the U.S. Surgeon General's guidelines for preventive sealants than are all children their age. For copies, contact Special Olympics Inc. at (202) 628-3630 or at [www.SpecialOlympics.org](http://www.SpecialOlympics.org)

## **Oral Health in America: A Report of the Surgeon General-Executive Summary**

**U.S. Department of Health and Human Services. *Oral Health in America: A report of the Surgeon General-Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000.**

This landmark report defines oral health and summarizes what is known about the oral health status of Americans, the impact of oral disease, the relationship between oral health and general health and well-being, the promotion and maintenance of oral health, and the needs and opportunities to enhance oral health. It highlights disparities in oral health and access to care for vulnerable populations (including special populations). The report concludes by recommending development of a National Oral Health Plan to change perceptions of oral health, accelerate the evidence base and translation of science, build an effective health infrastructure that integrates oral health effectively into overall health, remove known barriers that stand between people and oral health services and develop public-private partnerships to improve the oral health of those who still suffer disproportionately from oral diseases.

The report contains numerous implications for scientific investigation in the broad fields of basic and clinical research, epidemiology including behavioral, biological, and genetic elements, health promotion, quality of life measures, and the social-economic significance of oral diseases and conditions, among others.

Available at <http://www.nidcr.nih.gov/sgr/sgr.htm>.

## **Oral Reports: Dentistry is shifting to emphasis from drill and fill to antibiotics and biotechnology.**

**Genco RJ, Scannapieco FA, Slavkin HC. *The Sciences*, November-December 2000; 25-30.**

The authors discuss the “exponential change” in dentistry that is leading clinicians away from the “construction paradigm” of filling holes to molecular biology and biotechnology. “Instead of being fitted with false replacements, patients may one day be able to grow new enamel, bone, gums, and even entire teeth to replace damaged ones.” At the same time, the role of dentists will evolve: “Dentists will not only clean teeth and take X-rays; they will also screen for heart disease and intervene to help people quit smoking. Oral health will be understood as a barometer of an individual’s overall well-being. The authors predict that 30 years

from now, dental pain and tooth loss will be “ancient history” for all people who can access modern dental care.

## **Pediatric Provider Capacity for Children with Special Health Care Needs: Results from a National Survey of State Title V Directors**

**Limb SJ, McManus MA, Fox HB, MCH Policy Research Center, Maternal and Child Health Bureau, March 2001.**

A nationwide survey reveals that access to pediatric providers important to children with special health care needs varies by service, region, insurance status, and type of condition. Access was reported as best for inpatient hospital care and worst for dental care. Nearly 95% of Title V directors reported access to dental care to be a serious problem, with the greatest access difficulties apparent in the Northeast. Unlike the survey’s findings for other types of health services, the Title V directors reported greater barriers to dental care for “publicly insured” children. Children with cerebral palsy, developmental disabilities, and behavioral health conditions reportedly experience the greatest difficulties accessing oral health care.

## **Planning Guide for Dental Professionals Serving Children and Family with Special Health Care Needs**

**Isman B, Newton R, Bujold C, and Baer MT. *University of Southern California University Affiliated Program, Childrens Hospital Los Angeles, CA. 2000***

This guide was developed to assist dental professionals caring for children and families with special health care needs. It defines and elaborates on the components of family centered and child-oriented care in the context of children with special health care needs, providing specific suggestions for managing children in offices and discussing care with families. Available at <http://www.mchoralhealth.org/Addreports.html>

## **Relationship of Dental and Oral Pathology to Systemic Illness**

**Slavkin HC, Baum BJ. *JAMA* 2000; 284 (10):1215-7.**

The authors discuss the increasingly clear links between dental infection and systemic disorders such as arteriosclerosis, thrombosis, chronic cardiovascular

disease, cerebrovascular ischemia, and delivery of pre-term and low birthweight babies. “The essential contribution of dental and oral diseases to health maintenance is still not widely appreciated,” the authors suggest, in part because “oral and dental diseases are traditionally excluded from the medical curriculum.”

### **The Role of the Pediatrician in Oral Health of Children: A National Survey**

**Lewis CW, Grossman DC, Domoto PK, Deyo RA.**

**The role of the pediatrician in the oral health of children: A national survey. *Pediatrics*, Dec. 2000; 106 (6) 1-7; e- pages**

Pediatricians have an opportunity to promote oral health prevention during well-child care visits. But it is not clear to what degree pediatricians are knowledgeable about preventive oral health and whether they recognize barriers to their patients’ oral health care. The authors performed a national survey of pediatricians to assess their knowledge, current practice, and opinion of their role in the promotion of oral health, experience with dental decay among their patients, and willingness to

apply fluoride varnish. Of the 862 who responded, two-thirds reported observing caries in their school-age patients at least once a month; 55% reported difficulty achieving successful dental referrals for their uninsured patients; and 38% reported difficulty making referrals for their Medicaid patients. Among the dentists, 74% said they were willing to apply the fluoride. But although 90% of the pediatricians believe they have an important role to play in their patients’ oral health, half reported receiving no training in dental health issues during medical school. Available at: <http://www.pediatrics.org/cgi/content/full/106/6/e84>

### **The Handbook**

**Nowak AJ, ed. *The Handbook*. 2<sup>nd</sup> ed. Chicago: American Academy of Pediatric Dentistry; 1999**

This handbook summarizes critical information for dental professionals involved in care of children, and also contains a detailed listing of the oral health complications of a large number of special health conditions affecting children, and as such is a unique resource for dental and medical professionals caring for children with special health care needs.

# Health Promotion for Populations with Special Needs

Ruth Nowjack-Raymer, MPH, PhD

The goals of the conference *Promoting Oral Health of Children with Neurodevelopmental Disabilities and other Special Needs* are to develop both training and research agendas in oral health promotion. To accomplish these goals, it is imperative that a clear understanding exists about the meaning and dimensions of what on face value seems self-explanatory: health promotion.

Health promotion is a term that is widely used but often misused in the United States to denote activities designed by health professionals to educate individuals or the public about health behaviors. But research has demonstrated that when used alone, health education to prevent oral diseases has been neither effective nor efficient over the long term.<sup>1,2,3</sup>

Health promotion in actuality is much more than health education and involves sectors well beyond those focused on health care. Several important conceptual frameworks have emerged since the 1960s that help to articulate the multifaceted nature of health promotion. The concepts of health promotion that are fundamental to the deliberations of this conference and the formulation of research and training agendas are those that answer the following questions:

1. What are contemporary definitions of health?
2. What are contemporary definitions of oral health?
3. What is quality of life within the context of oral health?
4. What then is health promotion?
5. What are examples of oral health promotion actions that may have implications for training and research agendas for children with neurodevelopmental disabilities and other special needs populations?

## What are contemporary definitions of health?

To understand the term health promotion, we first must appreciate what the term health has come to mean. Historically, health was defined as the absence of disease. But as early as the 1960s, scholars began thinking of health in much broader terms that are of particular importance to children with neurodevelopmental disabilities and other special needs, their caregivers, and those who can influence their lives.

René Dubos stated that “health is not a state of being....It is a process of adaptation to the changing demands of living and the changing meanings we give to life.”<sup>4,5,6</sup> Key to this definition are the words “adaption” and “we.” Dubos clearly envisioned health as dynamic—not static, changing over the life course and with the

varying circumstances experienced throughout life. Through the use of the word “we,” Dubos broadened our thinking of who defines health from solely the health practitioner who provides diagnoses to include individuals and their perception of their own life situation.<sup>4,5,6</sup>

The World Health Organization further developed the concept of health to “the extent to which an individual or group is able, on the one hand, to realize aspirations and satisfy needs: and, on the other hand, to change or cope with the environment.”<sup>7,8</sup> Health is, therefore, a positive concept emphasizing social and personal resources, as well as physical health.” The WHO definition of health acknowledges that health is not solely dependent upon the individual and health professionals but rather also involves actions taken by society. For example, the aspiration that families of children with neurodevelopmental and other special needs may have for oral health may be mitigated by decisions of society about transport, finance, urban development, employment benefits including use of sick leave for dental appointments of children, accommodation on buses and in buildings, and discrimination.

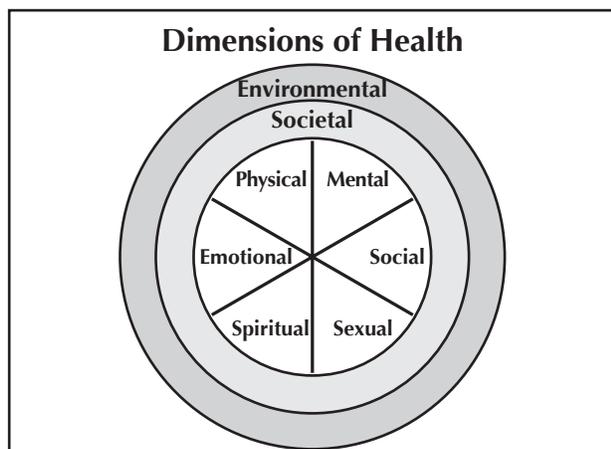
These broader definitions of health have led scholars to reflect on how an optimum state of health is defined and by whom. Seedhouse stated that, “optimum health is equivalent to the state of the set of conditions which fulfill, or enable a person to work to fulfill, his or her realistic chosen or biological potentials.”<sup>9</sup> Some of the conditions are of highest importance for all people. Others are variable dependent upon individual abilities and circumstances.” The ability to acquire essential nutrients is an example of a condition of the highest importance to all people that may be difficult for special needs children because of neurodevelopmental or other conditions affecting the oral, craniofacial complex.

Thus contemporary definitions of health are multidimensional. Figure 1 illustrates this well. The physical dimension of health is supplemented with the mental, social, sexual, spiritual, and emotional dimensions. All of these dimensions are in turn encapsulated within the broader societal and environmental dimensions that have powerful influences on individuals, their families and caregivers, and the community as they strive for optimum health.

## What are contemporary definitions of oral health?

Just as definitions of health have changed, so too have definitions of oral health. Not long ago, oral health care providers, academics, and researchers defined oral health status by presence or absence of carious lesions,

**Figure 1. Dimensions of Health<sup>10,11</sup> (adapted from Aggleston, Homans, 1987; Ewles, Simnett, 1992)**



filled or missing teeth, or depth of periodontal pockets. Now oral health includes the vast array of structures of the oral cavity and the contiguous structures known as the craniofacial complex and their sensory, digestive, respiratory, structural, and emotional functions.<sup>12</sup> Likewise, as the focus of oral health has broadened to additional structures and functions, so to has the definition of oral health evolved. Oral health is now defined as “A standard of health for the oral and related tissues which enables an individual to speak and socialize without active disease, discomfort, or embarrassment and which contributes to well being.” Sheiham states that the aim of oral health promotion efforts should be “to obtain and maintain a functional, pain-free, aesthetically and socially acceptable dentition throughout the lifespan for most people.”<sup>13</sup> These definitions of oral health expand our thinking of oral health well beyond that of solely clinical outcomes, and challenge researchers and clinicians to ask a broader range of questions. An example of such a question is whether the replacement of all missing teeth is necessary for adequate nutrition or aesthetic acceptability.<sup>14,15,16</sup>

Over the past several decades, it has become increasingly clear that a focus solely on disease status is not sufficient. The individual’s and caregiver’s perceptions of how oral health status affects life, as well as the importance of considering cultural and societal norms, are now thought to be essential components of oral health status. The measures of these additional domains of oral health are known as “oral health related quality of life indicators.”

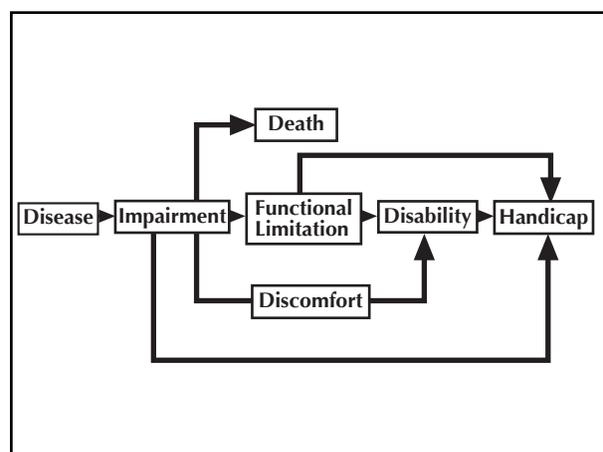
### What is quality of life within the context of oral health?

Generically, quality of life is concerned with the degree to which a person enjoys the important possibilities of life.<sup>17,18,19</sup> More specifically, oral health related quality of life includes the extent to which people identify that their teeth, mouth, dentures or other aspects of the craniofacial complex affect their ability to eat a full range of desired foods, the level of societal interaction that they have, the ability to speak clearly, the level of self confidence they have attained, and whether orofacial pain is a factor in activities of daily living.<sup>20,21,22,23,24</sup>

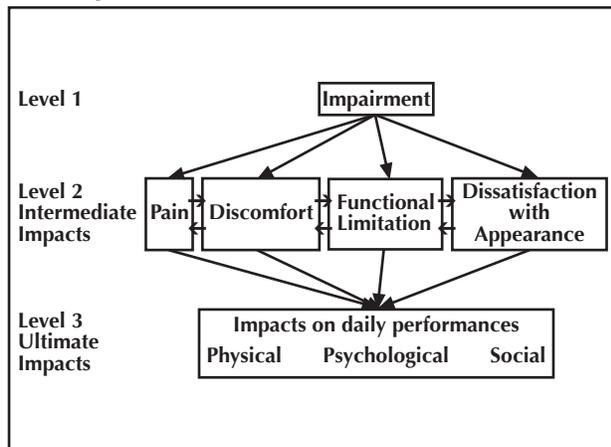
Oral health-related quality of life is of particular importance to this conference during the discussions of the research agenda for children with neurodevelopmental and other special needs and for the training agenda for the health professionals and others who provide care. Research and training issues might include the development and testing of oral quality of life outcomes for special needs children and their caretakers, the effectiveness of prevention and treatment modalities on improving oral health related quality of life, an exploration of what environmental factors affect oral health related quality of life, and the training of health professionals in assessing and using information related to the determinants of quality of life.

Several conceptual models have been developed by oral health researchers to aid in the exploration of the broader domains of oral health from the vantage point of those with impairments, disabilities and/or handicaps.<sup>25,21,26</sup> These conceptual models have evolved from the WHO International Classification of Impairments,

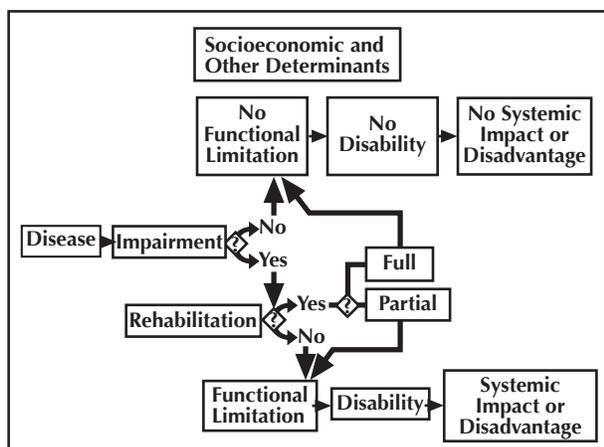
**Figure 2. Adapted from WHO Model of International Classification of Impairments, Disabilities, and Handicaps<sup>27</sup>**



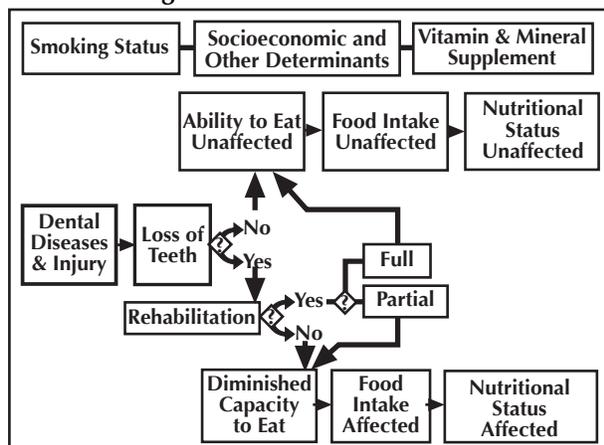
**Figure 3. Theoretical framework of consequences of oral impacts<sup>25,28,26</sup>**



**Figure 4a. Model of oral status impairment, functional limitation, disability, and systemic impact or disadvantage<sup>25,28,26</sup>**



**Figure 4b. Model of oral status impairment, functional limitation, disability, and systemic impact or disadvantage<sup>25,28,26</sup>**



Disabilities and Handicaps.<sup>27</sup> The models and the research associated with them provide other researchers, academics, and practitioners with a structured approach to assessing the impact of oral health impairments, disabilities or handicaps on multiple dimensions of quality of life and general health status (Figures 2-4).<sup>25,21,26</sup>

### What then is health promotion?

With an understanding that health and oral health are more than just the absence of disease, health is influenced by societal and environmental factors, and decisions about health should include the perspective of the individual, health promotion can be explored.

Health promotion emerged from a report issued by the minister of health of Canada in the mid-1970s.<sup>29</sup> The report clearly articulated that human biology and health care organization are not the sole factors that determine health—lifestyle as well as environment are of critical importance to health as well. Lalonde defined each element as follows:

“The human biology element includes all those aspects of health, both physical and mental, which are developed within the human body as a consequence of the basic biology of man and the organic make-up of the individual. The element includes the genetic inheritance of the individual, the process of maturation and aging, and the many complex internal systems in the body.”

“The health care organization element consists of the quantity, quality, arrangement, nature, and relationships of people and resources in the provision of health care.”

“The lifestyle element consists of the aggregation of decisions by individuals which affect their health and over which they more or less have control.”

“The environment element includes all those matters related to health which are external to the human body and over which the individual has little or no control.”

Lalonde stated that most of society’s efforts to improve health, and the bulk of direct health expenditures, have been focused on the health care organization, but when the main causes of sickness and death are identified, it is found that they are rooted in the other three elements. It is important to note that “environment” as used here is not just the air we breath and the water we drink but also the access to healthful, affordable, and acceptable foods; the extent to which the needs of families with children with special needs are supported within the community and workplace. Primary determinants of oral health are environmental. Examples of environmental factors that influence oral health status are water fluoridation, which

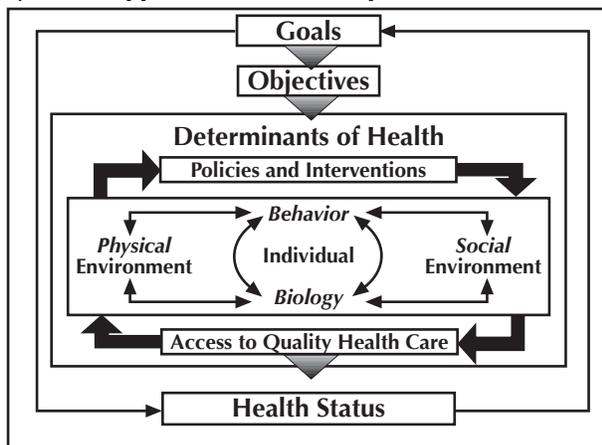
is a positive environmental factor and that requires community advocacy and support; and food policy, dealing with frequent sugar and carbohydrate consumption in day care or school. In the case of both of these examples of environmental determinants of health, advocacy and support beyond that of the individual are required.

Lalonde's report gave rise then to discussion worldwide and resulted in the WHO convening meetings around the issue of what determinants promoted health. From these meetings, the definitions of health promotion and the actions required for health promotion emerged.<sup>8,30</sup>

Health promotion is "a process that enables people to increase control over the determinants of health and thereby improve their health." Health promotion recognizes the need for change in the ways of living, the conditions of living, and the strategies to improve health include both personal choice and social responsibility.<sup>8</sup>

The landmark work of Lalonde and the WHO continues to influence health officials, health policy administrators and analysts, academics, and researchers. In the United States, the conceptual framework for Healthy People 2010 the Health Objectives for the Nation (U.S Department of Health and Human Services embodies the concepts of health promotion.<sup>31</sup> Looking at Figure 5, we see highlighted in the title the understanding that healthy communities are essential to attaining the goal of healthy people. The Healthy People in Healthy Communities conceptual model depicts at its center the determinants of health that include the interaction of individual biology, behavior, and the social and physical environment. The model clearly depicts that actions are necessary to influence these determinants and achieve the goals and objectives of health: the actions include access

**Figure 5. Healthy people in healthy communities, a systemic approach to health improvement**



to quality health care as well as the development and implementation of appropriate policies and interventions.

Similarly, the WHO suggests the following as Health Promotion Action Principles:<sup>30</sup>

1. Developing personal skills
2. Strengthening community action
3. Creating supportive environments
4. Building healthy public policy, and
5. Reorienting health services.

**What are examples of oral health promotion actions that may have implications for training and research agendas for children with neurodevelopmental disabilities and other special needs populations?**

This audience has extensive expertise as parents, pediatricians, pediatric dentists, dental hygienists, nutritionists, speech therapists, researchers of children with neurodevelopmental and other special needs. Each of you will bring to the discussion groups many ideas for the research and training agendas.<sup>33</sup> Below are Schou and Locker's explanations of the health promotion actions. In addition, examples of oral health promotion actions are provided as a starting point for discussions.

**1. Developing personal skills**

Explanation: Individuals as well as communities can take actions to improve their health. Information and education are necessary to enable individuals to make choices that promote health and enhance their ability to cope with the stresses and strains of daily life.

- Examples:
- Adaptive approaches for oral hygiene and preventive regimens
  - Skill-building in time management

**2. Creating supportive environments**

Explanation: Creating supportive environments means ensuring that the physical and social environments in which we live maximize the possibility of leading healthy lives. These supportive environments can be at the level of the family, the neighborhood, the community, or through the population health approach and common risk/health factor approach, which will be discussed later at a more widely distributed level.

Nancy Milio, a professor in public policy at the University of North Carolina, coined the phrase, "Making healthy choices the easy choices."<sup>33,34</sup> The phrase is very helpful as we think about what research initiatives might be undertaken to improve the health of our clients and

how the training of health care providers for new roles might be necessary.

Examples: The availability, accessibility, affordability, and acceptability of dental treatment services come to mind immediately. A few examples are mobile dental services, evening or weekend hours, and case managers who know the culture and language of clients and caregivers. Other examples of supportive environments that “make healthy choices easy choices” are:

- Making high concentration fluoride mouth rinses available over-the-counter and advocating that they be placed in a readily accessible area of groceries and pharmacies.
- Informing health care professionals, including pharmacists and clients and their caregivers, that sucrose free medications are available.

### 3. Building healthy public policy

Explanation: Actions can be taken at all levels of organizations and government that can promote or damage health. Building healthy public policy means working to ensure that all levels of organizations and government take into account the potential health effects of the policies and actions they develop and implement and ensure that health promoting policies be implemented. These include diverse sectors of the community, city, state or nation such as transportation, housing, commerce, education, energy, and agriculture.

Examples: Building healthy public policy requires the education of decision makers and advocacy on the part of caregivers, organizations, and health professionals. Both the research and training agendas could include items related to the building of healthy public policy. Some of the items that may be considered are:

- Appropriate levels of remuneration for health promotion, prevention, and treatment
- Flexible leave policies for families to seek needed care
- Healthful and appropriate feeding practices in day care centers and schools
- Relaxation of practice acts that restrict the provision of oral health services, such as using dental varnish in pediatricians’ offices
- Statutory, health care, and voluntary sectors working together to assess the implications for health in all public policies including transport, education, leisure, agriculture, housing, and employment

### 4. Strengthening community action

Explanation: Public participation at the community level is vitally important. Communities can identify priorities, plan strategies, and implement actions that will improve health. In addition, communities can increase their abilities to recognize factors that may be detrimental to health and take actions to improve the situation.

Example: Support skill development within the community to take leadership roles for health advocacy and health policy development around issues of oral and general health for children with neurodevelopmental and other special needs.

### 5. Reorienting health services

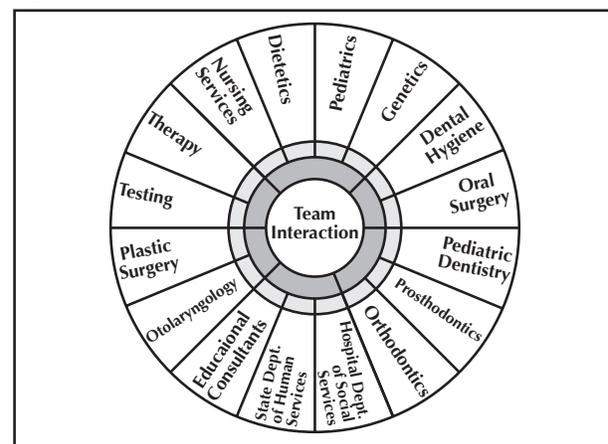
Explanation: Health services traditionally have been concerned with curing diseases. The health care system needs to expand beyond the provision of clinical services to address the needs of individuals and communities. Mechanisms to encourage this expansion must be developed by those who fund health services and others.

Examples: Focus on health promotion and primary prevention, and participate in interdisciplinary and transdisciplinary approaches.

Some of the very best examples of interdisciplinary oral health care come from the literature related to the care of children with neurodevelopmental and other special needs. The multiple sectors used by a dental hygienist who served as coordinator of care for children with cleft palate are depicted in Figure 6.<sup>35</sup>

I was asked several years ago to review the literature and discuss at an international meeting opportunities and barriers to integrating oral health into the general health sector.<sup>35</sup> Many of the health promotion actions that must be carried out for the oral health of children with neurodevelopmental and other special needs are in

**Figure 6. Coordination of a cleft palate team**



sectors outside the traditional dental clinic and require interdisciplinary and transdisciplinary skills that may not be a part of the current dental school curriculum. One of the most poignant statements I found during the review of the organizational management literature was that of Wise.<sup>36</sup> In reference to the research that he had conducted with interdisciplinary medical teams, Wise stated, “It was naive to bring together a highly diverse group of people and expect that, by calling them a team, they would in fact behave as a team. It is ironic indeed to realize that a football team spends 40 hours per week practicing teamwork for the two hours of Sunday afternoon when teamwork really counts. Teams in organizations seldom spend even two hours per year practicing when their ability to function as a team counts 40 hours per week.”<sup>36</sup>

An item on both the research and training agendas of this conference regarding the reorientation of oral health services toward the promotion of health amongst children with neurodevelopmental disabilities and other special needs may be skill development to serve on interdisciplinary, collaborative teams. Table 1, an adaptation from the work of Wise, underscores the differences in characteristics of a traditional dental team versus that of a collaborative team—the type of team that is essential to children and families with multiple challenges.<sup>36</sup>

Health promotion action also requires a diverse array of roles beyond that of the clinician. The United Kingdom has created a master’s degree professional category of health promotion specialist, and other health care professionals receive as a part of their education exposure to health promotion concepts. No such specialty exists in the United States at this time, thus expanded roles of dentists and dental hygienists may be an important training agenda item.

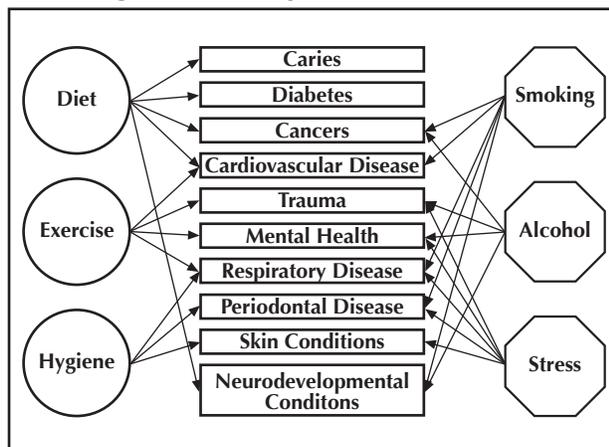
A search of the literature showed that during the mid-1980s, dental hygienists suggested that their education and role of be expanded to include health educator, administrator, change agent, researcher, consumer advocate, and health promoter.<sup>35,37</sup> These roles are consistent with those of the health promotion specialist of the United Kingdom. It appears that these suggested curriculum enhancements for dental hygienists have not occurred to date. The training agenda for oral health promotion should include consideration of appropriate curriculum changes for students and continuing education for existing professionals.

Even if the education of dentists, dental hygienists and other health professionals were reoriented toward the health promotion concepts discussed, the resources to influence health promotion action principles would remain insufficient. An important emerging concept in health promotion is the common risk/health factor approach. Sheiham and Watt have explored this concept for oral health related issues.<sup>38</sup> As is depicted in Figure 7, the central concept underlying the integrated common risk/health factor approach is that the promotion of general health by influencing a small number of risk factors such as diet, hygiene, and tobacco use may have a major impact on a large number of diseases (including oral diseases) at a lower cost and greater efficiency and effectiveness than disease-specific approaches. Sheiham and Watt suggest that savings in resources may be attained by coordinating the work done by various specialty groups and organizations around issues that are common to several health conditions.<sup>38</sup> Decision makers and individuals may be more readily influenced by measures directed at preventing cancers, diabetes, and heart disease as well as dental caries than if disease-specific recommendations were made alone.

**Table 1—Characteristics of a traditional dental team versus a collaborative health care team.<sup>35</sup>**

	<b>Traditional Dental Team</b>	<b>Collaborative Team</b>
Purpose	Specific treatment/health education	Comprehensive care
Priorities	Same for all members	Varies along discipline lines
Tasks	Clearly delineated and limited	Numerous, somewhat unclear
Locations	Self-contained environment	Variety of settings
Personnel	Roles clearly defined	Ambiguous, may overlap
Communication	More one-way	Group problem-solving
Decisionmaking	Autocratic	Team of colleagues, less clear authority; compromise frequent
Leadership	Hierarchical	Shifting, depending on topic

**Figure 7. Common risk/health factor approach to oral and general health promotion<sup>38</sup>**



The common risk/health factor approach to oral and general health promotion encourages a multisectorial approach to health and distributes the resources across the population rather than at a few disease-specific at-risk groups.<sup>39</sup> Training and research implications of the common risk/health factor approach are many, and they point to the need for health professionals to develop a range of advocacy, health policy, and communication skills to enable them to work with other health professionals and sectors outside of health and influence change toward the improvement of health for all.<sup>40</sup>

### Conclusion

Health is more than the absence of disease. Health promotion is more than health education directed at personal behaviors. Health and health promotion involves individuals, community, and larger society and necessitates a broad range of actions. Health promotion actions require interdisciplinary and trans-disciplinary approaches and multiple skill packages to carry out diverse roles. Health promotion action and the roles of health care providers and the community are supported by the common risk/health factor approach.

The health promotion approach can serve as a catalyst for research and training agendas and changes that will benefit not only the health and oral health of children with neurodevelopmental and other special needs but also that of the general population.

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# Dental Caries and Periodontal Disease Made Simple

Joel H. Berg, DDS, MS

## Introduction

Dental caries is the most common infectious disease in mankind. It affects nearly 97% of the population. Its effects account for 60% of the approximately \$60 billion expenditure for dental goods and services in the United States each year. It generally results in the need for small and large dental restorations (fillings), as well as crowns, root canal therapy, and sometimes dental abscesses causing significant health complications. In spite of the fact that dental caries affects virtually everyone, it is essentially preventable.<sup>1</sup> We have the technology today to prevent most of dental caries, and its result (cavity formation). But due to issues of access to care,<sup>2</sup> particularly disparities in access,<sup>3,4</sup> most people do not obtain proper prevention and can exhibit significant caries manifestations.<sup>5</sup>

Periodontal disease can cause loss of teeth,<sup>6</sup> and it can be rapidly progressive, particularly when manifested as Early Onset Periodontitis, often resulting in the loss of permanent teeth in children and adolescents.

This paper will briefly describe the rudiments of dental caries and periodontal disease, as well as their effects on systemic disease and their occurrence and manifestation within special populations. The effect of systemic diseases on periodontal health will also be introduced.

## Dental caries

Dental caries is the process of demineralization and subsequent cavitation (cavity formation) in teeth,<sup>7,8</sup> caused by acid production when oral bacteria<sup>9</sup> ferment carbohydrates. Each time fermentable carbohydrates are presented to the mouth,<sup>10</sup> and therefore to the oral flora, they will be metabolized into acids that have the potential to demineralize enamel when the pH drops to 5.5. This pH drop occurs immediately after any kind of “sucrose challenge.” Normally, salivary buffering capacity,<sup>11</sup> along with the remineralization potential of fluorides will reverse this demineralization process and will prevent the formation of an actual caries lesion manifested as a “cavity.” One can see how diet—in terms of frequency of sugar challenge<sup>12</sup>—is important in the initiation and progression of dental caries. The more acid are challenges<sup>13</sup> to the enamel surface relative to remineralizing opportunities, the greater the chance that an actual surface defect will develop.

The example of early childhood caries<sup>14</sup> provides a model environment wherein the infant has frequent exposures to a sugar containing substance (milk),<sup>15</sup> without commensurate opportunity to allow these formative lesions to remineralize.<sup>16</sup> The scenario that unfolds here has often been described as a kind of a tug

of war where the battle is won in the direction of greater force.<sup>17,18</sup> In spite of aggressive attempts to control plaque via oral hygiene measures and to aid remineralization with accelerated fluoride regimens, an *ad lib* exposure to sugar<sup>19</sup> such as is the case in early childhood caries can cause devastating outcomes.<sup>20</sup> Not every child with inappropriate feeding patterns will exhibit a rapidly destructive manifestation of dental caries. Virulent strains of bacterial plaque must be colonized to allow the acid<sup>21</sup> production to persist and cause caries lesions to progress rapidly.

Factors that promote caries include elevated levels of oral microflora, a high sucrose (frequency)<sup>22</sup> diet, poor plaque control, inadequate flow of saliva, inadequate fluoride exposure,<sup>23</sup> inappropriate bottle feeding, and a compromised medical history.

Medical providers are generally the first to examine the mouth of a child and therefore have the first opportunity to recognize dental disease. They may recognize risk factors that contribute to higher susceptibility to disease, including odontogenic infections.<sup>24</sup> The risk of dental caries includes the interplay of three principle factors: the host (saliva and teeth), the microflora (oral biofilms), and the substrate (diet—content and frequency of exposure), as well as time.<sup>25</sup> A determination of risk must take into account the interaction between these various components. Caries experience, extent of plaque present, as well as various social and behavioral factors are all contributors to caries risk.

Whereas dental caries is preventable with the proper use of three basic implementations (diet, hygiene measures, and fluoride introduction),<sup>26,27</sup> risk assessment must result in an appropriately blended recommendation that combines an individual recommendation with what would be empirically recommended on a population basis.<sup>28</sup> In fact, even basic preventive intervention has been shown to be as effective as intensive intervention within a caries-active population of 12 year-olds.<sup>29</sup>

One of the barriers in preventing caries in children is the fact that generally, one cannot clinically detect its presence until such stage that it must be treated with surgical (restorative dentistry) techniques.<sup>30</sup> This is because the standard techniques for caries detection (visual examination with mirror, lighting, and explorer as well as with radiographs) cannot detect the presence of a caries lesion until it has progressed about halfway through the depth of the enamel (or about .5 mm in primary teeth).<sup>31</sup> At this stage, the benefits of fluoride, in combination with a change in diet and hygiene practices, can have minimal outcome for those lesions detected in

this crude fashion. Therefore, the standard recommendations for prevention of dental caries are empirical in nature and are intended to prevent or reverse lesions that are not normally detectable.<sup>32</sup>

Several new techniques, such as enhanced digital radiography<sup>33,34</sup> as well as quantitated laser fluorescence, (QLF)<sup>35,36</sup> when fully developed over the next several years, will detect dental caries clinically at a very early stage. It is at this early stage of caries detection that remineralization with fluoride or other remineralizing agents may be very effective.<sup>37</sup> This change in diagnostic ability for dental caries will change dental care in a dramatic fashion. It will also likely precipitate the development of remineralizing agents that work better than fluoride or in conjunction with fluoride.

### **Implications for educating the pediatric medical care provider**

A recent paper reported that most emergency room visits related to non-traumatic dental disease result from dental caries or dental abscess initially related to dental caries.<sup>38</sup> The role of the emergency room in connecting with dental personnel to access comprehensive dental care for the patient is critical. The number of visits to the medical care provider by children in their pre-school years significantly exceeds the number of visits to the dentist.<sup>39</sup> This provides enhanced opportunities for risk assessment and referral of children at risk for dental disease in their early years.

Caufield and coworkers established that children experience a “window of infectivity”<sup>40</sup> during which the *Mutans Streptococci* and other bacterial species responsible for dental caries can be transmitted from parent to child. If virulent strains are not transmitted during this window (from about 14 months to 30 months of age), then the child will likely never be inoculated with virulent organisms. New work continues to evolve in this arena, much of which will have significant impact on how we manage risk assessment and caries prevention.

There are significant associations between caries experience and socioeconomic status,<sup>41</sup> nationality,<sup>42,43</sup> and sucrose content of the diet.<sup>44</sup> Intervention with preventive programs, including appropriately modified diet, oral hygiene, and fluoride exposure, can positively affect the caries experience of children.

The recent implementation of fluoride varnishes<sup>45</sup> is an appropriate means of delivering low dose/continuous release mode of fluoride for patients in need. In addition, there is a recent re-awareness regarding the benefits of remineralization<sup>46,47</sup> on enamel surfaces, including the appropriate use of fluoride in various forms, and the usage of xylitol containing chewing gum<sup>48,49,50</sup> toward

this end. There are separate issues related to the use of chewing gum as habit that may otherwise be undesirable, but it is clear with gum that much of the effect may be the mechanical cleaning of tooth surfaces after sugar exposure in addition to the xylitol effect.

Dental caries remains a significant problem in the United States and around the world, although the demographics of its manifestation within the population have shifted significantly. Most caries disease exists within a small portion of the population. It is this subset that should be the focus of our attention. Screening populations by virtue of risk for caries based on a multitude of factors is essential to our ability to provide the access to care<sup>51,52,53</sup> and preventive and surgical treatment for caries in the appropriate way.

### **Periodontal disease**

Periodontal disease is a chronic bacterial infection that affects the supporting structures of the teeth, including the gums and the bone supporting the teeth.<sup>54</sup> If left untreated, in some cases, it can progress to tooth loss.<sup>55</sup>

The mildest form of periodontal disease is gingivitis, or inflammation of the gingiva (gums)<sup>56</sup>. It is manifested by swollen gums that bleed easily, although generally exhibiting little discomfort. Plaque bacteria attach to the tooth surface above and below the gum line, and this can trigger a host inflammatory response.<sup>57,58</sup> This host response causes the breakdown of tissue responsible for periodontal disease. Although pathogenic bacteria must be present to precipitate periodontal disease,<sup>59</sup> it does not occur in the absence of a host immunological response to these pathogens. Periodontal disease is actually a variety of diseases, some acute in their presentation and some more slowly progressive.

### **Early-onset periodontitis**

Early-onset periodontitis affects individuals 35 and younger.<sup>60</sup> It is usually characterized by rapidly progressive bone/attachment loss<sup>61</sup> and usually with defects in the host immune response. The most rapidly progressive form of early onset periodontitis is generally associated with neutrophil dysfunction, allowing rapid progression of the disease.<sup>62</sup>

### **Systemic disease and periodontitis**

Children with insulin-dependent diabetes mellitus are at significantly greater risk of periodontal disease, particularly when their diabetes is not well controlled. Gingivitis is the predominant form of periodontitis in children and adolescents, and gingivitis will progress to periodontitis much more readily and quickly in diabetic children.

Healthy children (without periodontitis) rarely have cultivable organisms responsible for periodontal disease (*A. actinomycetemcomitans* and *P. gingivalis*)<sup>63,64,65</sup> whereas these organisms are cultivable in more than 20% of children exhibiting periodontitis.

Plaque, in general and without speciation, causes immediate acute reaction in the form of gingival inflammation and bleeding upon probing within most children. Interestingly, children exhibiting the juvenile form of periodontitis rarely exhibit dental caries, as the organisms responsible appear to be incompatible with one another.<sup>66</sup> There is also some evidence that various oral herpes viruses at least contribute to the severity of periodontal disease in children.<sup>67</sup>

### **Prevention and treatment of periodontal disease in children**

Whereas diet hygiene and fluoride (remineralization) regimens must work together to achieve optimum outcome in caries prevention, it is clearly oral hygiene<sup>68</sup> that stands out as most important in the prevention of gingivitis and periodontitis in children.<sup>69</sup> The removal of “local factors” (plaque and calculus) is essential in averting an acute inflammatory response within the gingival tissues—the first step in the periodontal disease process.

Many clinical studies show the clear link between plaque scores and gingivitis scores in children.<sup>70,71</sup> In spite of this, children with significant accumulations of plaque and therefore significant gingivitis rarely exhibit progression to periodontal attachment loss. Apparently, the host immune response in children, in the absence of an immunocompromising state, will halt the disease at the gingivitis level. Chemotherapeutic agents, such as chlorhexidine, have also been shown to be effective in improving the gingival health of adolescents.<sup>72</sup> Although stannous fluoride<sup>73</sup> has been used for such treatment as well, its effect is not as great as chlorhexidine.

Treatment of gingivitis and periodontitis in children consists primarily of debridement of local factors (professional cleaning). If the disease has progressed to the level where attachment loss exists, then traditional surgical therapies used in adults must be employed.

### **Influence of systemic health on periodontal health**

Recently, much attention has been directed to the influence of periodontal health on systemic health.<sup>74</sup> Although much of this work has been shown in the adult population, it is important to note significant examples of such an oral-systemic link in the child as well.<sup>75,76,77</sup>

It is also clear that periodontal inflammation is more prevalent in children exhibiting certain systemic

diseases,<sup>78,79</sup> as already mentioned regarding diabetes. Some syndromes, such as Papillon-Lefevre Syndrome,<sup>80</sup> always result in severe periodontal consequences. In spite of aggressive antibiotic therapy in these patients, they generally will lose all of their teeth, with rapid progression of the disease. This is a rare example of where even with aggressive control of local factors and chemotherapeutic intervention, the periodontal disease is uncontrollable. Conversely, although it is well established that phenytoin<sup>81</sup> induces gingival overgrowth in most of its users, the level of overgrowth is strongly related to the level of hygienic control of local factors (plaque).<sup>82</sup> Even in the case of (immunosuppressed) HIV-positive children, when the local factors are well controlled, we do not see significantly more periodontal disease.<sup>83</sup>

Periodontal disease is rarely as significant a problem in children as is dental caries. Dental caries affects nearly all children some way, although the severe forms are concentrated within underserved populations. Periodontal disease in children is prevalent in the form of gingivitis, whereas most children perform inadequately when it comes to their oral hygiene. In spite of this, rarely does this gingivitis progress to periodontitis in children, as often is the case in adults.

Whether speaking of dental caries or periodontal disease, prevention measures are quite effective in averting disease progression. It is therefore appropriate to institute the best methods of risk assessment as a first step toward this objective.

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# Historical and Research Perspectives

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## Historical perspective

An understanding of oral health care research issues for children with neurodevelopmental disorders and other special health care needs requires 1) a historical perspective of the field and 2) a conceptual framework to view advances and areas for further research. The history has four critical movements:

1. The pediatric dentistry specialty, formalized in the late 1940s, owned care of children with special health care needs children well into the mid-1990s, and legitimized scientific inquiry into care of these patients over the last generation.
2. The Academy of Dentistry for the Handicapped (ADH), formed in the mid-1950s, which organized the fervor of clinicians into an empirical yet viable set of techniques, which still is the infrastructure of care for children with special health care needs today.
3. Societal recognition of developmental disorders during the Kennedy era leading to federal programs, academic liaisons, and the first organized workforce in dentistry devoted to clinical and research pursuits for those with children with special health care needs.
4. Landmark grants to dental education by the Robert Wood Johnson Foundation (RWJ) to train mainstream dentists in care of the disabled, which inoculated dental education with dentists focused on special patients.

Federal maternal and child health programs, fellowships sponsored by advocacy groups such as United Cerebral Palsy, and existence of the Federation of Special Care Organizations discussed later in this report are all examples of diverse professional interest spawned by one of more of these movements.

An awareness of the above speaks to the nature of research and why, today, we have limited understanding of and largely empirical support for care of these children. The practitioner base, whether specialty or general practice, has been immersed in techniques that have been perpetuated without benefit of scientific validation. Necessity, not controlled clinical trial, has been the mother of invention, in care of children with children with special health care needs. The academic community most closely related to care of these children has been primarily devoted to educating future clinicians rather than engaged in systematic research. Occasional trickle-down benefits of medical research into disabilities has occurred, as has translation of mainstream oral health research into the disabled population. To suggest

that research into special health care needs in dentistry has been long-standing, directed, or significant is to be wrong three times!

With this understanding, we can identify reasons why areas for research into children with children with special health care needs are ripe. Historical priority for care, a very limited workforce, and a workforce focused on care have impeded research. Also, within our own professional lifetimes, we have seen a parade of terms — infirmed, crippled, handicapped, special, exceptional, disabled, developmentally disabled, challenged and today, special needs — to describe an ever-changing group of patients. Federal priorities for dental research, while demonstrating a long-term interest in basic science issues with craniofacial importance, only recently have taken on disparities which include care of the majority of the children with special health care needs population. Finally, consider that when we were children and well into our young adult lives, prevention of disability, systemic therapy and survival drove special care needs research. Oral health was not even on the map.

So, in summary, one message of the paper is that research has been very limited and empiricism reigns in oral health for the children with special health care needs population.

## Educating dentists to care for children with special health care needs

Newacheck et al. report that one of the most prevalent unmet health care needs for children with special health care needs is dental care.<sup>1</sup> Although reasons and associated factors are many and include insurance coverage, family income, race, and ethnicity, we know little about availability of dental practitioners to treat this population. Training programs in dentistry and educational guidelines to prepare practitioners to treat patients are major components of access.

As early as the 1920s, some dental students treated patients in hospitals, asylums and homes for the incurable, feeble minded, crippled, deaf and dumb. Gies<sup>2</sup> recommended strongly the development of special clinics for dental treatment of children in all dental schools. At that time, only five of 43 schools had specific clinics providing dental treatment for children. By the 1930s, post-doctoral programs in pedodontics were promoted in 14 institutions treating healthy normal children as well as those with medical histories and some who were “crippled.”

During the next 25 years, graduate programs in pedodontics grew to 18 and postgraduate programs increased

to 17 with one program specifically designated for pedodontics—cerebral palsy study. These programs continued to provide experience didactically and clinically in care of children with special health care needs as well as the normal child. In the 1940s, with the formation of the American Academy of Pedodontics and in the 1950s, with the establishment of ADH, members with mutual interest had organizations to rally around and promote pediatric comprehensive preventive programs, behavior management, early recognition of developing malocclusions and treating children with special health care needs. In the 1960s, the Office for Maternal and Child Health (MCH) with additional funding from Title X of the Social Security Act, increased the number of dental training programs. Between 1967 and 1975, a budget of over \$3 million supported three to six programs, producing 191 trainees. The emphasis was to train pedodontists with special emphasis in managing children with special health care needs. In the 1970s, the budget for programs supported by MCH fluctuated dramatically. At one time, up to six programs were funded annually to train specialists in pediatric dentistry and special patient care. At the present time, MCH supports two Centers for Leadership in Pediatric Dentistry Education, with an annual budget of approximately half a million dollars.

With the development of the University Affiliated Facilities Program in 1963 and transition to the University Affiliated Programs (UAP) in 1987, dentistry was included in 78 disciplines involved in interdisciplinary training. Although the total numbers of trainees has been great, dental trainees were only 2% of the total. In 1994, MCH redirected its investment in UAPs to Leadership Education in Neurodevelopmental and Related Disabilities (LEND), most of which are in UAPs. Pediatric dentistry is included in the 12 disciplines represented.

The National Institute of Dental Research at one point was involved in training pedodontic postdoctoral students. In the 1960s, it established a fellowship in pedodontic programs with an emphasis on dentistry for patients with special health care needs anticipating that these trainees would assume academic positions in universities and institutions to train others to treat patients. In the five years of the program, eight trainees were supported, with three trainees assuming academic dentistry and research positions. Unfortunately, this program was short lived.

Advocacy organizations like the Easter Seal Society and the United Cerebral Palsy Association supported programs for pedodontic education. In return, the programs cared for patients with special health care needs in the community. To the best of our knowledge, none of these programs exist any longer.

During this time, local and regional programs funded either by states or local advocacy organizations trained dentists to treat special patients. Well known programs in Philadelphia, Boston, Chicago, Pittsburgh, Dallas and San Francisco played an important role in training dentists and especially pedodontists.

In 1973, RWJ made available \$4.7 million to support up to 11 projects in dental schools for the expansion or development of programs geared to the predoctoral student, with the emphasis on patients with special health care needs. A follow-up study, in 1983, comparing students trained in the 11 RWJ programs with students from universities without a program, reported that trained students had a willingness to treat handicapped patients and the attitude toward treating the handicapped was improved.<sup>3</sup> When they began private practice, differences between the two groups were relatively small but consistent. In all but a few specific conditions, experiences of the non-program graduates were similar to those of the graduates of the programs that had special training programs. With the discontinuation of the programs, many dental colleges continued programs and clinics to provide opportunities for dental students with patients with special health care needs.

Even though the American Academy of Pedodontics was organized in 1947, it was not until 1965 that the American Dental Association (ADA) recognized specialties. Up until then, pedodontic training programs varied greatly in curricular content and the ADA Commission on Dental Accreditation was charged to work with the specialty to develop educational guidelines for advanced programs. Over the years, standards in pediatric dentistry have been revised four times and have always reflected the importance of the special patient. The definition of the specialty of pediatric dentistry has also reflected changes in the scope of practice of the specialty. In 1996, the most recent definition was approved by the ADA House of Delegates.<sup>4</sup> To date we are the only specialty that includes patients with special health care needs in its definition.

How about the rest of the practitioners in dentistry? In the 1996 Standards for Predoctoral Education that provide guidelines for undergraduate education in dentistry, Standard 2.25 states, “Graduates should be competent in providing oral health care within the scope of general dentistry as defined by the school for the child, adolescent, adult, geriatric and medically compromised patient.”<sup>5</sup> This sounds great, but the school has considerable discretion on how to satisfy the standard. In a recent report<sup>6</sup> on predoctoral education in special care dentistry, 71% of the faculty who responded to the survey felt students graduating from their schools were qualified to provide dental care for special needs

patients. Earlier in the report, only 53% of the schools reported less than five hours of classroom instruction and 29% of the schools between five and fifteen hours. In 73% of the schools, less than 5% of a student's total clinical experience is spent in treating patients with special needs. In light of the limited didactic and clinical experiences, it is questionable how well-prepared predoctoral students are to treat patients with special health care needs.

Two surveys address pediatric dentists and their continuing treatment of patients with special health care needs. In 1989, Nowak et al.<sup>7</sup> reported that in a typical week, 57% of responders treated up to 50 patients with special health care needs. When asked the importance of caring for special health care needs patients, 83% reported it a very important activity. In 1998, another survey of a convenience sample of the members of the American Academy of Pediatric Dentistry<sup>8</sup> asked questions about their management of patients with special health care needs. Ninety-five percent of respondents routinely scheduled patients with special health care needs. Interestingly, 95% of them integrated them into the routine schedule and almost 71% of them continue to follow them after 21 years of age. Almost 95% reported that their buildings were handicapped-accessible and over 96% said that their office was handicapped-accessible. Looking at changes that may have occurred over five years, respondents stated that a large percentage of their practice is made up of patients with special health care needs and these numbers remain high. These two surveys infer that 1) pediatric dentists are overwhelmingly involved in treating patients with special health care needs as a routine in a normal activities and schedules of the office and 2) the need to treat these patients has remained high over the years in practice.

Can pediatric dentists continue to maintain this level of activity and are there other practitioners who will be able to join us? Over the years there have been regional programs (e.g., Long Island Jewish Hospital, DECOD program at the University of Washington, Regional Dental Center at University of Iowa) available to practicing dentists. All of these programs had successes, but their overall impact would probably be rated as minimal. Two additional advanced education programs provide a variety of experiences with special patients. General practice residency programs (hospital -based) and the advanced general dentistry programs (dental school-based) are available to dentists upon completing their formal training. A substantial number of graduates apply to these programs, but their standards suggest rather than mandate experience with patients with special health care needs. These programs are dependent upon hospital or government funds. More recently, Title

VII funds have provided increased dollars to support additional programs and trainees. A recent change has also occurred with the availability of Graduate Medical Education funds so that dental programs have additional resources to increase the number of residents trained in the dental specialties.

While most physical barriers to care have been removed due to the Americans with Disabilities Act, advocates for special patients continue to report physical barriers to access. Finding a dentist to treat special patients also remains difficult in many communities. The reported lack of training, reluctance to treat special patients, and inaccessible buildings and offices all increase the inability of the special patient to receive treatment.

Pediatric dentists, though few in number, disproportionately serve the special needs population when compared to other dentists. Pediatric dentistry training programs are even having difficulty. In a recent survey,<sup>9</sup> program directors reported substantial increases in patients with special health care needs compared to five years earlier. The wait to have dental treatment in the operating room for children in pain and discomfort was 28 days, while managing a patient for dental care with conscious sedation was 36 days. University and hospital based dental programs are an important source of dental care for children with special health care needs, so increasing program size and facilities is most important.

In summary, pediatric dentists continue to be major providers of dental care for children with special health care needs. Support from other dentists has improved over the last 10 years, but at this time too few dentists care for patients with special health care needs.

### **Problem-oriented approach to care**

As stated earlier, an elusive ever-changing definition of the population remains a problem, if not in application of information, then in searching for it! Even more daunting may be categorizing existing literature in functional terms. One way is to employ a problem-oriented approach, as suggested by Entwistle and Casamassimo.<sup>10</sup> Table 1 briefly describes the parameters of such an approach that replaces diagnoses with real problems or care issues, emphasizes commonality across conditions, and accounts for severity and mixed conditions. Similar real-world approaches have recently emerged in the medical literature on children with special health care needs.

### **What do we know and how good is the information?**

The remainder of this paper addresses areas of research into children with children with special health care needs, using the problem-oriented topical approach.

Table 2 shows a summary of a cumulative manual review of over 1100 literature citations for level of evidence. This is not meant to be an exhaustive review, but covers mainstream and some obscure literature on the topic of care for patients with disabilities. The predominant category of report (>97%) is classified as Level III (expert opinion, case reports, descriptive studies). A very small minority of studies demonstrates dramatic results in the absence of good controls and might qualify as Level II-3. A “best evidence” computerized search for dentistry and the handicapped revealed no citations.

**Accessibility.** Accessibility to care is highly influenced by availability of trained and willing providers, which is addressed above. Physical accessibility has been diminished as a problem with passage of the Americans with Disabilities Act, and as noted above, practitioners report accessible offices. Research questions remaining for access to care relate to provider willingness to see various types of patients, their abilities to handle various disabilities, transition of care from pediatric dentistry to general practice, and the effectiveness of centralized specialized care versus care dispersed across a community. These are issues common to medical care for children with special health care needs such as those with cystic fibrosis, hemophilia, and congenital heart disease.

**Psychosocial obstacles.** Recent research<sup>1</sup> confirms that oral health can be a pressing need for families with children with special health care needs. Preoccupation with medical management of disorders, including competing therapies, association of pain with any health care delivery, and lack of understanding of a connection between oral and systemic health are all aspects of this problem. Research is needed to better understand ways to assure that children with special health care needs receive needed oral health services within their overall health care. Available literature is largely descriptive.

**Financial.** The association of disability with low income and other health disparity markers needs to be studied further to determine the importance of financial obstacles in oral health for children with special health care needs. Clearly, competing medical costs, family breakup with its associated financial effects, effects of disabilities on parental employment, and insurability of the child are other issues that need to be studied further. The difficulty gaining access to care strongly suggests that government programs are not adequate to ensure care for this population. The literature on financial issues is not focused on the children with special health care needs and is largely descriptive.

**Communication.** The use of medication to manage behavior as a substitute for communication with children with special health care needs undergoing oral health care is perhaps the most studied area in this population. Essentially all studies are descriptive or compare varying regimens of sedation. In spite of numerous studies, consistently effective regimens with an acceptable level of safety remain elusive. Choice of therapy based on disability has never been shown to be possible in the dental setting except for general anesthesia, which has been shown universally effective, but costly.

**Mobility and stability.** Patient positioning and control of untoward movement for dental care is highly empirical. A large unproved armamentarium of manufactured and cobbled devices is available in the literature and used daily by practitioners under the “it works in my hands” proviso of care for the special patient. The vast majority of literature reports are technique descriptions and reviews. Areas for research would include desensitization therapies, management of perioral sensitivity, hyperreflexia and oral-motor dysfunction. Clearly, investigation of the negative effects of poorly applied devices on care seeking and compliance as well as patient safety is needed.

**Prevention.** Techniques to reduce caries and periodontal disease have been well-researched. Tooth brushing, both manual and motorized, appears effective. Chlorhexidine has been shown to be effective and some higher level evidence exists using research designs that employ randomization and control. While one might make the assumption that what works in the general population also works with the children with special health care needs ignores the effects of medications, salivary and oral-motor dysfunction and dietary alterations and gross motor deficiencies. Research is needed to study the effect of risk factors imposed by disability as they relate to currently available prevention techniques.

**Treatment planning issues.** Little evidence supports clinical pathways for children with special health care needs based on function, life-span or mainstreaming issues. Dental needs have not met with the same scrutiny or emphasis as medical or educational needs and because of that, precious little outcome data exist to support care patterns and choices other than expert opinion.

**Medical problems.** A large body of descriptive studies identifies the medical factors important in care of children with special health care needs. This systemic-oral relationship has looked at oral infection and cardiovascular health, systemic causes of dental abnormalities, and the interactions of dental and medical

medications in the care of children with special health care needs. Research is needed to translate these warnings and clinical opinions into best practices and clinical care guidelines.

**Continuity of care.** The role of oral health care within the comprehensive care of children with special health care needs has been looked at historically from the perspective of interdisciplinary teams. Cleft lip and palate, hemophilia, and oncology are examples of conditions in which dental-medical collaboration places oral health at the level of importance of team member. Most data supporting these types of programs are descriptive with some measures of improvement in

prevalence data. More recently, case management of children with special health care needs oral health has been used to enhance compliance and outcomes. Again, most supporting data are descriptive or expert opinion.

### **Summary**

Education of dental personnel in care of children with special health care needs has evolved over the last half century and current programs may prove to be inadequate to provide the necessary number of skilled providers. Research into care of children with special health care needs is largely descriptive and the body of treatment literature is based on expert opinion and empiricism.

**Table 1—Problem areas in care delivery for patients with special health care needs**

<b>Problem Area or Issue</b>	<b>Definition</b>	<b>Selected Sub-Areas</b>
Accessibility to Care	Patient can receive care from a community dentist in a timely manner, in a way consistent with the general population	<ul style="list-style-type: none"> <li>• Building access</li> <li>• Transportation</li> <li>• Attitudes</li> <li>• Workforce readiness</li> <li>• Office Procedures</li> </ul>
Psychosocial Obstacles	Patient seeks care, has appropriate attitudes toward oral health and appropriate anxiety levels	<ul style="list-style-type: none"> <li>• Self-image</li> <li>• Preoccupation with disability</li> <li>• Anxiety about oral health care delivery</li> <li>• Non-medical dysfunction issues such as mental illness or cultural mandates</li> </ul>
Financial Problems	Patient has adequate resources to pay for care or qualifies for assistance and has income to support indirect costs of oral health care	<ul style="list-style-type: none"> <li>• Insurance coverage</li> <li>• Employment issues</li> <li>• Financial skills</li> <li>• Competing costs of care</li> <li>• Income level</li> </ul>
Communication	Patient has the ability to receive, process, and respond to provider-initiated communication in the course of treatment	<ul style="list-style-type: none"> <li>• Sensory disorders</li> <li>• Processing difficulties</li> <li>• Office noise</li> <li>• Interpreters</li> <li>• Communication devices</li> <li>• Effects of medication</li> </ul>
Mobility and Stability	Patient is able to be treated in conventional dental operatory, with or without reasonable physical accommodation by either dentist or patient	<ul style="list-style-type: none"> <li>• Reflexes</li> <li>• Contractures</li> <li>• Deformities</li> <li>• Personal devices (catheters, respirators)</li> <li>• Professional devices (papoose board, restraints)</li> <li>• Obesity</li> </ul>
Preventive	Patient's motivational, dietary, medical, and physical needs are met with a preventive plan that optimizes oral health	<ul style="list-style-type: none"> <li>• Attitude toward oral health</li> <li>• Special diets</li> <li>• Physical limitations for personal oral hygiene</li> <li>• Medication oral effects</li> </ul>
Treatment Planning	The individual needs of the patient are recognized and accounted for in a dental treatment plan	<ul style="list-style-type: none"> <li>• Lifestyle</li> <li>• Life span</li> <li>• Income</li> <li>• Quality of life</li> <li>• Functional needs</li> </ul>
Medical Status	The patient's medical status is compensated for so that negative emergent or long-term consequences of dental care are prevented	<ul style="list-style-type: none"> <li>• Infections</li> <li>• Respiratory distress</li> <li>• Disseminated coagulation</li> <li>• Anaphylaxis</li> <li>• Drug interactions</li> </ul>
Continuity of Care	Patient receives necessary integral dental, medical, and supportive adjunctive care to maximize oral health	<ul style="list-style-type: none"> <li>• Dental specialty care</li> <li>• Medical co-therapy</li> <li>• Special services (e.g. speech)</li> <li>• Case management</li> </ul>

\* Literature has been grouped into major topical areas; each area may represent multiple reports, studies, and expert opinions.

**Table 2—Topical assignment\* of level II-A and III evidence by the problem-oriented approach**

<b>Accessibility</b>	<b>Financial</b>	<b>Psychosocial</b>
Effectiveness of Physical Barriers Practitioner Attitudes Wheelchair Access Wheelchair Devices Mobile Dentistry (Vans) Architectural Designs Education of Dentists Practice Management Barriers Attitudes of Dentists	Cost of General Anesthesia Treatment Times Estimation Medicaid and Care of Disabled Workshop Employment Medical Costs Medical Necessity and Dental Treatment Payment alternatives Cost of Treatment Alternatives	Social Indices of Handicaps Parental Opinions and Perceptions Community Placement Effects Institutionalization Effects Family Issues Dental Neglect Effects of Chronic Illness and Disability
<b>Communication</b>	<b>Mobility and Stability</b>	<b>Medical</b>
Behavior Management Sensory Impairment Reflexia Pain Perception Assessment of Behavior Effects of Behavior Management Techniques Visual Impairment	Restraints Sedation Techniques (Partial Listing of Drugs) Midazolam Ketamine Propofol Chloral Hydrate Nitrous Oxide Diazepam Combinations IV Sedation General Anesthesia Mouth Props Limited Oral Opening Headrest Modifications Dental Chair Modifications Castillo-Morales Devices Miscellaneous Devices and Techniques	Bacteremia Gastroesophageal Reflux Paraplegia Tube Feeding Phenytoin/Seizures Orthopedic Problems Iron Lung Problems Autism Dementia Drooling Miscellaneous Disabilities

**Table 2 (continued)**

Treatment Planning	Prevention	Continuity of Care
Crown Contours Orthodontics Periodontal Needs/Status General Anesthesia Multi-modal Prosthetics Occlusal Status Oral Surgery Radiographic Techniques Comparison of Treatment Estimation of Treatment Need Tooth Mortality	Education in Institutions Health Promotion Use of Chlorhexidine Preventive Programs in Institutions Fluorides in Disabled Patients Recall Intervals Mouthrinsing Electric Toothbrushes Hygiene Devices Toothbrush Modifications Motivational Tools/Programs	Referral to Dental Specialties Referral to Medical Specialties Related Medical Needs and Therapies Legal Issues Special Olympics and Other Community Programming Aging and Care of Disabled Provider Education Mouthsticks General Practice and Care of the Disabled Social and Medical Influences Outpatient Management Role of the Dental Hygienist Social Worker Roles Community Based Services

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\*All references represent Level III evidence

# Evidence-based Approaches to Oral Health Promotion

James J. Crall, DDS, ScD

## Overview and objectives

The federal Maternal and Child Health Bureau's definition of children with special health care needs includes "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type or amount beyond that required by children generally.<sup>1</sup> Eighteen percent of U.S. children and adolescents ages 18 and under (or 12.6 million children and adolescents) have a chronic illness or disability. Although findings of studies of prevalence and severity vary, there is general agreement that common oral diseases, developmental disturbances, and acquired conditions are an important consideration for the oral health and general well-being of children with special health care needs.

At the same time, there is general consensus that the adverse impacts of many of these diseases and conditions can be minimized through the effective application and, in some cases, adaptation of approaches that have been demonstrated to promote oral health<sup>1</sup> in children. Thus the objectives of this paper are to:

- Compare the prevalence of common oral diseases and craniofacial conditions in children with special health care needs and their use of oral health care services.
- Evaluate the evidence for the effectiveness of various oral health promotion modalities (highlighting findings that deal particularly with these children) using a relatively simple conceptual model of oral health promotion.
- Examine environmental and policy issues that warrant attention.
- Offer conclusions and recommendations concerning promising oral health promotion strategies for children with special health care needs and additional considerations.

No national studies have been conducted to determine the prevalence of oral and craniofacial diseases among the various populations with disabilities.<sup>2</sup> Data on the oral health of and utilization of services by children with special needs generally are limited to studies of individuals with a particular relatively common condition (e.g., mental retardation) or aggregated for individuals

who meet the broad definition of these children, but whose diagnosis or diagnoses may vary. Consequently, evaluations of relevant literature often reflect more of a composite analysis rather than a series of global findings.<sup>ii</sup> The evidence cited and assessed below is drawn from recent reviews of such studies and, while extensive in scope, is not the product of a comprehensive, systematic, evidenced-based analysis of available literature.

## Prevalence of conditions

*Dental caries (tooth decay):* Horowitz et al.<sup>3</sup> recently reviewed available data concerning the oral health of individuals with mental retardation (MR) and concluded that it generally is poorer than that of their peers without MR. They further concluded that "although there are inconsistent findings on the prevalence of dental caries among individuals with MR compared with the general population, the majority of evidence suggests that individuals with MR have more untreated caries than those in the general population. Given that treatment of caries is a prevalent and accepted part of good health behavior for much of the world, this lack of treatment, even in developed countries, suggests problems in access to dental services."

*Gingivitis and periodontal diseases:* Likewise, available evidence suggests that individuals with MR are likely to have a higher prevalence of gingivitis (inflammation of the gums) and other periodontal diseases (loss of connective and bone tissue that support the teeth) compared with the general population. But the prevalence of these oral health conditions among individuals with MR is dependent on age, etiology of MR, and living situation.<sup>3</sup> Horowitz et al.<sup>3</sup> also noted that "Older individuals with MR are at higher risk for poor oral health compared with younger individuals with MR and those in the general population. Further, individuals with Down Syndrome are more likely to have gingivitis compared with individuals in the general population. Additionally, although increased surveillance may influence the prevalence of disease detected, individuals living in institutions are at increased risk for gingivitis and other periodontal diseases compared with individuals in the general population."

*Oral hygiene:* Although a growing number of scientific studies continue to support the role of specific bacteria

i. This paper uses the following as a definition of "oral health": "a standard of health of the oral and related tissues which enables an individual to speak and socialize without active disease, discomfort, or embarrassment and which contributes to well-being." [Department of Health. An oral health strategy for England. 1994]

ii. Literature reviewed for this paper often reflect findings from individuals with different conditions that meet the definition of CSHCN. Efforts have been made to identify specific groups where possible.

in various oral diseases (i.e., the specific plaque hypothesis), good oral hygiene is widely regarded as an important measure to prevent oral diseases among individuals with MR. According to a recent pilot study of consumers of Montana Developmental Disability services (79.8% of whom had mental retardation), Traci et al.<sup>4</sup> found that the estimated prevalence rate of oral hygiene problems was 451 per 1,000 individuals with developmental disabilities. Interestingly, those with mild MR appear to have poorer oral hygiene when compared with those with moderate or severe MR, chiefly due to the increased supervision of those with more severe MR. This suggests that efforts to improve the oral hygiene of individuals with mild MR may be a particularly effective intervention.<sup>3</sup>

*Malocclusions and developmental disorders:* Malocclusions can occur due to congenital or acquired misalignments (crowding) of the teeth or jaws. In a national study of individuals between 8 and 50 years old (not limited to children with special health care needs), 11% were found to have severe crowding,<sup>5</sup> while about 9% had a posterior crossbite, where there is poor contact of the upper and lower chewing surfaces. This crossbite was most common in non-Hispanic whites. Severe overjet—where the upper front teeth project far forward—was found in approximately 8% of this population, with a similar percentage demonstrating a severe overbite—where the front top and bottom teeth greatly overlap when the mouth is closed. While the true prevalence of malocclusions in children with special health care needs is unknown, these children are prone to develop malocclusions as a result of abnormal developmental processes and musculature function.

Numerous developmental disorders affect the oral, dental, and craniofacial complex.<sup>2</sup> These include congenitally missing teeth (teeth that do not develop); congenital problems involving tooth enamel, pulp, or dentin; and craniofacial birth defects or syndromes. Cleft lip and palate are the most common congenital anomalies and may occur as isolated defects or as part of other syndromes. Other craniofacial defects and syndromes that have been the focus of recent genetics research include ectodermal dysplasias, Treacher Collins syndrome, Apert's syndrome, and Waardenburg syndrome. Craniofacial defects and syndromes have many serious consequences including unusual facial features; severe functional problems; and the need for extensive surgical, medical, and rehabilitative interventions and prosthetic devices.

Oral and facial trauma—injuries to the head, face, and teeth—are very common. They can range in severity

from the very mild to those that cause death. Although injuries have a major impact on oral health, data on the number and severity of head and face injuries in the United States are very limited.<sup>2</sup> Overall, 25% of all persons aged 6 to 50 have had an injury that resulted in damage to one or more anterior teeth.<sup>6</sup> An estimated 2.9 million emergency room visits for all age groups corresponded to tooth or mouth injuries between 1997 and 1998. Twenty-five percent of these injuries were seen in children under the age of 4.<sup>7</sup>

### Use of health services

Studies generally indicate that individuals with MR or other special health care needs, especially those residing in smaller community-based facilities, do not receive adequate dental health care. Nearly two-thirds of community-based residential facilities report that inadequate access to dental care is a significant issue.<sup>8</sup>

*Strength and limitations of the evidence:* Similar to studies on the prevalence of MR and other conditions, research efforts on health care service use by individuals with disabilities and children with special care needs are scarce. Studies that do address service use in this population tend to focus on non-representative samples of the population.

### Unmet oral health care needs

Parents consistently report dental care as one of the top needed services for their children with disabilities regardless of age.<sup>9</sup> Results of the 1994-95 National Health Interview Survey on access to care and use of services by children with special health care needs indicate that dental care is the most prevalent unmet need of children under 18 years of age.<sup>10</sup> Overall, 8.1% of these children were reported unable to get needed dental care; roughly 6% with public or private insurance had difficulty getting care; and nearly 24% were uninsured.

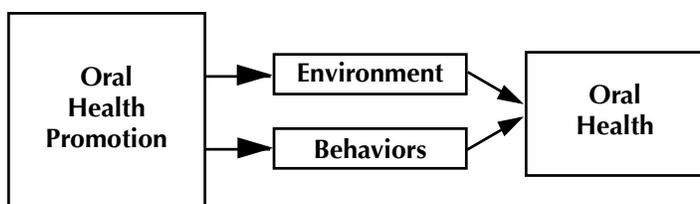
Newacheck et al.<sup>10</sup> also reported that the following groups of children in general (i.e., not just those with special health care needs) younger than 18 were reported to be at significant elevated risk for unmet dental needs:

- Poor and near-poor children (more than four times as likely than those from middle- and upper-income households)
- Uninsured children (four times as likely as insured children)
- Children of single-parent or no-parent households (20% more likely)
- Children who have compromised health status or limited activity (20%-60%)

- Children residing in the Western United States or in non-metropolitan areas (20%)
- Older children (230%—320%)<sup>iii</sup>

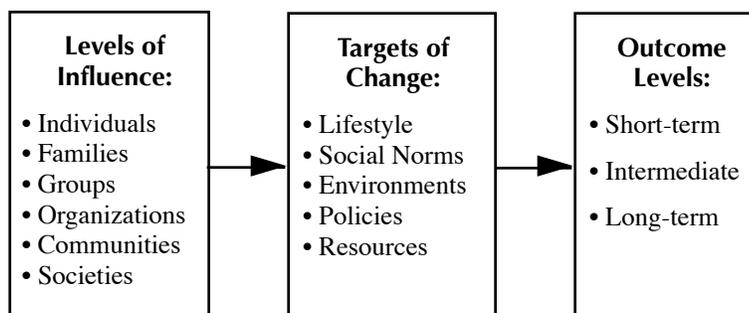
### Oral health promotion

The diagram below illustrates a relatively simple, yet practical general conceptual framework for oral health promotion, adapted from Green.<sup>11</sup> It conveys that effective health promotion activities can be used to alter an individual's or population's environment (broadly speaking) or behaviors to yield improvements in health (oral health in this case). Environmental changes can include changes in one's physical or social environment, or changes in policies and programs that serve to promote better oral health. Changes in behaviors can include activities performed by an individual (e.g., improved self-care preventive dental practices) or others responsible for the care of an individual, a dimension that is very important when it comes to children, especially those with special health care needs.



### Levels and targets of health promotion change

Oral health promotion can target individuals, families, groups within a population, a variety of organizations, entire communities, or even society as a whole. Similarly, oral health promotion can target changes in lifestyles, social practices, environmental changes, policy development or modification, and development or organization of resources. Linkages are shown in the following diagram, adapted from Green.<sup>11</sup> Outcomes generally occur along a time continuum, with short-term changes being easiest to achieve but difficult to sustain (e.g., tooth brushing or flossing behaviors); intermediate outcomes serving as indicators that underlying situations ultimately influencing health are being altered (e.g., reductions in risk factors or greater sense of empowerment); and long-term outcome changes reflecting ultimate desired goals (e.g., improvements in health or quality of life and effective community or societal organizations or programs).



### Evidence-based oral health intervention approaches

Kay and Locker<sup>12</sup> recently conducted a systematic review of the effectiveness of health promotion aimed at improving oral health. Additional reviews of the effectiveness of various approaches for preventing or managing dental caries also have been completed of late by way of a National Institutes of Health (NIH) Consensus Development Conference on the Diagnosis and Management of Dental Caries Throughout Life<sup>13</sup> and a Canadian Task Force on Preventive Health Care (CTFPHC).<sup>14</sup> Although the methods employed in these reviews varied slightly, they generally agree in their findings and focus on findings from literature that meet the criteria for U.S. Clinical Preventive Services Task Force Levels I, IIa, and IIb. Because of time and space constraints, primary emphasis is placed on studies related to dental caries. Results are summarized below.

### Community-based interventions:

- Water Fluoridation—Fluoridation of drinking water is widely regarded as effective, cost-efficient, and of great importance in the primary prevention of dental caries for individuals throughout their lifespans. Water fluoridation and other measures that do not require individual skills or compliance are particularly important for children with neurologic disorders and should be viewed as the foundation for all oral health promotion efforts.
- Fluoride rinses—The CTFPHC found good evidence for daily or weekly fluoride rinse programs for those with very active decay or a high risk of caries but poor evidence for recommending rinses for the general population.

iii. Epidemiologic data based on clinical examinations from NHANES III show that younger (i.e., preschool) children have the greatest likelihood of having untreated decayed teeth. Differences between NHANES III and NHIS results likely reflect parents' or caregivers' lack of awareness of unmet dental needs in young children.

- **Dental sealants**—Both the NIH and CTFPHC documents found good evidence for the effectiveness of pit and fissure sealants in the primary prevention of dental caries when properly applied and maintained. The CTFPHC particularly encouraged their selective application on permanent molars within three years of eruption in children with high risk of caries.
- **Oral health education**—Numerous studies have demonstrated the effectiveness of providing information on oral health using a variety of methods for the purposes of increasing knowledge and altering attitudes and behaviors. Kay and Locker<sup>12</sup> concluded that these approaches were invariably effective in increasing knowledge levels, with complex and more technical education methods adding little benefit (i.e., simple provision of information was sufficient to increase knowledge). With respect to altering behaviors and attitudes, oral health promotion methods generally were successful in altering reported attitudes and beliefs. But studies that included assessments of behavior changes generally found little evidence that education efforts alone were effective in achieving improved behaviors.
- **Mass media campaigns**: Kay and Locker reviewed seven studies relating to mass media oral health promotion campaigns. By and large, these studies suggested that mass media promotions were ineffective for promoting either knowledge or behavior change. But because the evaluation methods used in these studies were considered to be inadequate, no specific conclusion regarding their role in improving oral health can be drawn.

## Health behaviors

*Use of fluoride toothpastes:* The CTFPHC recommended that everyone should use a fluoride toothpaste (dentifrice) daily as part of regular oral hygiene (plaque control), noting that supervision should be provided to young children to prevent swallowing of excess toothpaste. Kay and Locker noted that almost all studies that involved use of fluoride toothpastes as part of tooth brushing programs in schools showed that the significant reductions in caries incidence demonstrated in these programs were related to the fluoride, not to differences in lifestyle (i.e., adoption of tooth brushing habits without concomitant use of fluoride). Intervention effects are related to the length of time between initiation of the program/practice and the time of evaluation, with effectiveness being demonstrated in programs/practices that were sustained for at least six months. Interventions with less than daily frequency generally show no evidence of caries reductions.

*Plaque control:* Available evidence shows that although daily brushing and flossing do not prevent caries, they are a part of good plaque control practices and help to control gingival disease. Evidence suggests that simple instructions can alter individual's behavior in the short term, but that ongoing effectiveness requires periodic reinforcement. Elaborate programs appear to be no more beneficial than simple approaches. School-based programs have not been shown to affect oral hygiene, but may reduce caries if fluoride toothpaste is applied daily. Educating parents about plaque control in their offspring has been shown to be effective.

*Nutrition counseling:* Although widely employed, evidence for the effectiveness of positive oral health-related changes in the diet in the general population and dental counseling to induce positive dietary changes is poor. Nevertheless, counseling is recommended for individuals at high risk for caries, including counseling parents to change infant feeding practices that have been linked to early childhood caries (e.g., long-term feeding from baby bottles containing caries-promoting liquids).

## Clinical and caregiver approaches

*Topical fluoride applications:* There is good evidence to support annual or biannual (twice per year) applications of acidulated phosphate fluoride gels, particularly for those with active caries or at high risk of caries. Data also support the use of fluoride varnishes, although studies documenting their effects on caries in primary teeth is less complete and consistent.

*Antimicrobials:* Data regarding the effectiveness of chlorhexidine gels and varnishes in the management of dental caries and periodontal diseases is promising, but evidence concerning chlorhexidine rinses as a caries intervention are lacking.

*Combined approaches:* Evidence suggests that combinations of fluoride, chlorhexidine, and sealants generally are effective, particularly in children and high-risk individuals; additional studies are needed, however, to identify the best combination of interventions for particular individuals or groups within the population.

*Treatment of active disease:* Investments in basic science research and product development have resulted in a variety of safe and effective methods for individuals for whom prevention modalities have not been successful and who therefore require treatment of the consequences of common oral diseases and conditions. Largely lacking, however, are studies of the relative effectiveness and cost-effectiveness of these various restorative and rehabilitative approaches in the population at large or for specific groups within the population (i.e., clinical outcome studies or health services research). Also

largely lacking are studies that clearly elucidate the extent, magnitude, and impact of various barriers that adversely affect access to services that are recognized as safe and effective.

### **Environmental and policy issues and recommendations**

A host of broad environmental factors and policy issues also must be considered in order to develop interventions that have credible evidence for their use. Time and space constraints do not allow for full elaboration of these issues; a brief summary of some of the more prominent considerations are included below.

- Individualized health promotion education—Knowing which methods or interventions work for the general population does not ensure that they will be either effective or efficient in special populations. Translational research is necessary to adapt the general findings of basic and clinical studies to the needs and constraints of different groups, such as children with special health care needs. Given the shortcomings of our current health care system, caregivers are often relied on to coordinate the care of their charges. Caregivers should be provided with training, in order to help them understand how to recognize health problems and access appropriate care.
- Education of health care providers—One reason that the health care system does not adequately provide care to children with special health care needs is that providers do not feel equipped to treat them. The curricula and training for all health care providers should be reviewed and updated to include specific education on conditions included in the definition of special needs children and effective approaches for providing health care services to them. This should include, in addition to classroom hours, clinical experiences as well as didactic information. In addition, guidelines should be developed to help ensure the quality of care and to raise providers' confidence in treating children with special health care needs.
- Surveillance—Population-based data at the national and state levels (as opposed to small, non-representative convenience samples) are necessary to determine accurately the health needs of the population of children with special health care needs on an ongoing basis and monitor the effectiveness of new programs and interventions. Effective periodic oral health surveillance strategies, perhaps using Title V funding, need to be developed and implemented.

- Health services and policy-related research—As noted above, studies of the relative effectiveness and cost-effectiveness of health promotion, prevention, and treatment approaches in the population at large or for specific groups within the population such as children with special health care needs are sorely lacking and warrant development to advance the health of these children and serve the needs of policy makers, program administrators, and caregivers. Also necessary are studies that clearly elucidate the extent, magnitude, and impact of various barriers that adversely affect access to services and evaluation studies to identify and disseminate information on “best practices.” The United States has invested in biomedical sciences related to oral health and has gained many advantages for large portions of the U.S. population. But the consequences of a general failure to invest in research and policy development that translates basic research findings into effective interventions that benefit all children, especially children with special health care needs, also is patently evident.

### **Summary and conclusions**

In summary, available evidence provides considerable support for a variety of oral health promotion activities that have been shown to be successful. There are, however, few studies demonstrating the effectiveness, cost-effectiveness, or modifications necessary to extend these findings to populations of children with special health care needs. U.S. oral health research enterprise has invested considerable resources in biomedical science and product developments that have resulted in benefits for large segments of the population. Nevertheless, millions of children with special health care needs have not fully benefited from these investments in basic research and product development. Similarly, little attention has been directed to research or policy development that would extend the benefits of the prior investments to those who are arguably most vulnerable to oral diseases and conditions.

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## Development of Health-promoting Behaviors

Norman S. Braveman, Ph.D.

“Most of what I really need to know about how to live, and what to do, and how to be, I learned in kindergarten. Wisdom was not at the top of the graduate school mountain, but there in the sandbox at nursery school.... These are the things that I learned: share everything. Play fair.... Clean up your own mess.... Don't take things that aren't yours. Say you're sorry when you hurt somebody. Wash your hands before you eat. Flush. Warm cookies and cold milk are good for you. Live a balanced life. Learn some and think some and draw and paint and sing and dance and play and work every day some. Take a nap every afternoon. When you go out into the world, watch for traffic, hold hands and stick together.... The Golden Rule and love and basic sanitation. Ecology and politics and sane living.” (*All I Ever Really Needed To Know I Learned In Kindergarten* Robert Fulghum, 1988)

The purpose of this paper is to provide a framework for a research agenda on the developmental aspects of health-promoting behaviors. Robert Fulghum's statement of health promotion seems like an appropriate starting point in order to stay anchored in “real life”: information gained from the scientific study of health promotion matters only insofar as it has an impact on the lives and health of people.<sup>1</sup> Moreover, Fulghum's quote, in which the answers to questions about adult health are sought in early life, addresses the main point of this conference. He also seems keenly aware of the complexity of what constitutes health-promoting behaviors. Thus he includes in his list of things that lead to a healthy life, individual sanitation and proper nutrition as well as meaningful interpersonal interactions, political action, and societal change. Unfortunately, he doesn't refer to one of the most basic and effective childhood health-promoting behaviors: tooth brushing with fluoride-containing toothpaste.

Inglehart and Tedesco, after a thorough review of the literature on the influence of family on oral health, conclude that the earlier oral health care habits are established in a child's life, the greater the likelihood that they will be maintained.<sup>2</sup> Presumably, this holds for other health-promoting behaviors. Interestingly, two of the earliest emerging forms of self-directed health-promoting behaviors by children in some cultures are hand washing and tooth brushing. On the surface, there

appear to be several elements common to these two behaviors, not the least of which is the fact that both closely mirror their respective adult behaviors. And while both can be effective in preventing disease, this is not always the case. Health-promoting behaviors are not always successful in preventing disease, nor is their non-use a guarantee that dire consequences will occur. And the conditions under which the behaviors are acquired are often the same. Children, knowing virtually nothing about the germ theory of disease, engage in hand washing and tooth brushing upon the urging of their adult caregivers. Nevertheless, somehow children acquire the behavior and, for a subset of these children, even carry the behaviors into adulthood.

What are the behavioral mechanisms that underlie the acquisition of each of these behaviors so that children come to engage in them without being coerced or reminded? Is the acquisition of one behavior during childhood facilitative of the other, or are they totally independent of each other? Is there a general positive attitude toward health promotion that can result from early childhood training with behaviors such as tooth brushing or hand washing that, in turn, makes the acquisition of other health-promoting behaviors easier later in life? Or does the individual need to be trained to engage in each behavior separately at each developmental stage?

If hand washing and tooth brushing are the foundation for adult health promotion behaviors, what are the behavioral mechanisms that ensure their continuation into adolescence and then adulthood? Is there a critical period in childhood for the acquisition of these behaviors? How does it happen that some people (both children and adults) exhibit health-promoting behaviors and others don't? And how does it happen that some people exhibit health-promoting behaviors under some conditions and not others? There are many reasons why the study of the development of health-promoting behaviors is important. Unfortunately, the research literature available to answer these and many other questions about health-promoting behavior is sparse to non-existent. The good news is that the scientific literature isn't totally devoid of potentially relevant information. One has to extrapolate quite a bit, however, and realize that we are dealing with speculation and not fact. I suspect that in the end we will pose more questions that we will answer. But this process will hopefully lead to the beginnings of a research agenda.

## What is health promotion?

According to the World Health Organization (WHO), *health promotion* is a process that enables people to increase control over the determinants of health and thereby improve their health.<sup>3</sup> Earlier, Harris and Guten introduced the concept of *health-protective behavior*, defined as “any behavior performed by a person, regardless of his or her perceived or actual health status, in order to protect, promote or maintain his or her health, whether or not such behavior is objectively effective toward that end.”<sup>4</sup> This definition stresses the importance of the individual’s beliefs of what may be health promoting, independent of whether there is any objective evidence to support their use.

An important related concept is Rotter’s *internalized locus of control*, the process by which individuals come to expect that things that they do will produce a particular outcome, in this case a state of health.<sup>5</sup> A related concept is Bandura’s health *self-efficacy*, the confidence that a person has in his or her ability to behave in a way that produces a desirable outcome.<sup>6</sup> The desirable outcome here is health, and in the context of this conference, our interest is in uncovering antecedents found in childhood to health-promoting behaviors that may occur in adulthood. And more specifically, we are interested in discovering what difference it makes if, during the period of acquisition, a child has a chronic disease or condition.

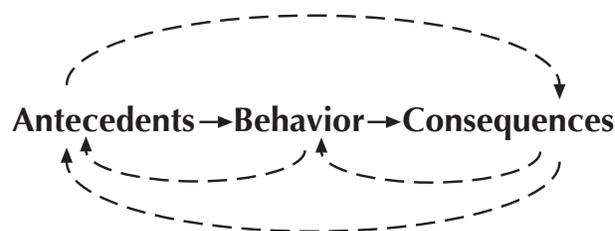
## The ABCs of behavior: a practical model

One approach to organizing the way in which we approach the study of the development of health promoting behavior is what I call the ABC’s of behavior. In this model A, B, and C refer, respectively, to the antecedent(s), behavior(s), and consequence(s) involved in health promotion. Antecedents may be short-acting discrete stimuli (hunger) or setting conditions (i.e., longer acting complex events or combinations of events, sometimes thought of as providing a context within which behavior can occur such as motives, moods, physiological conditions, environmental factors, health/disease status, etc.). Antecedents set up conditions for the behavior to occur, which leads to consequences, which can in turn modify the antecedents or the behavior. Consequences that are effective reinforcers are usually temporally or spatially related to the behaviors, or seem logically related (i.e., stomachache after eating certain new food).

It is important to recognize that there are other equally valid models that could be used. We selected the ABCs of behavior for its simplicity, utility, and heuristic value. It is a dynamic model insofar as each of the elements influences, and in turn, is influenced by each of the

others. An illustration of the interplay of these elements looks something like the figure below. The solid-line arrows characterize what are considered to be direct causal relationships and the broken-line arrows characterize elements that are thought to influence each other as opposed to being related through direct causation:

## The ABCs of Behavior



For purposes of this conference, I believe that we are more interested in setting conditions, as opposed to discrete stimulus events, for example:

- Stage of cognitive and intellectual development
- Chronological or developmental age
- Culture and ethnicity
- Health status and congenital or inherited disease, acute or chronic disease
- Nutrition and exercise
- Knowledge about health and disease
- Socioeconomic status
- Education
- Neighborhood or place of residence

Regarding behaviors, we are interested particularly in those that promote health and reduce disease risk, including such acts as exercise, good nutrition, stress-reducing activities, hand washing, tooth brushing and flossing, exposure to fluoridation through drinking water or tooth paste, non-use of tobacco products, safe sex, and moderate use of alcohol. Less obvious health-promoting behaviors might include political activities that lead to improvements in air quality or in access to health care or education that increases an individual’s understanding of the causes of a particular condition.

In their simplest form, consequences can be viewed as reinforcements (i.e., any event that increases the chances that the behavior will be repeated when similar antecedents occur), punishments (i.e., any event that decreases the chances the behavior will be repeated), or neutral (i.e., something happens, but it has no affect on behavior).

Consequences of behavior can become antecedents for another set of behaviors. Also, some consequences can have an impact on the antecedents. For example, if a food treat is the consequence of a given behavior and the setting condition was hunger resulting from food deprivation, then the ingestion of the food will modify the hunger and thus change the subsequent reinforcing value of food. At some point in time, when the person or animal becomes totally satiated, food can (or should) lose its reinforcing value.

In the vast majority of instances, psychologists and especially, parents of small children have found that to be effective, consequences must be spatially and/or temporally contingent on the behavior in question. In order for a reinforcement to increase the probability that a desired behavior will be repeated, for example, the reinforcement needs to happen very soon after the desired behavior occurs. Similarly, for a punisher to have its desired effect it should occur soon after the unwanted behavior. While there are notable exceptions to this generalization, one of which we will discuss in a moment, more often than not the ‘contingency of consequence principle’ is quite important in controlling behavior.

At some level, consequences should be perceived by the individual as being related to the behavior. This is known as the “stimulus relevance principle.” Suppose an individual eats sushi for the first time. In the middle of the night, he wakes up sick. On his way to the bathroom in the dark, he bangs his toe and breaks it. Now even though he really doesn’t know what caused him to become ill, he is not likely to eat sushi in the very near future because, he surmises that it was the sushi that made him sick. (He won’t say that he’s avoiding sushi because he broke his toe, even though it occurred at about the same time.) According to the stimulus relevance principle, gastrointestinal malaise is the natural consequence of ingesting something disagreeable and thus is more readily associated with eating than with pain from breaking one’s toe. The stimulus relevance principle also helps us understand that consequences can be powerful controllers of behavior, even when they occur hours after the behavior occurs or in a different environment.

Health-promoting behaviors seem to fall into the class of behaviors whose consequences may not be immediately apparent to the individual. There may be other factors that might help us understand how health behaviors become associated with their consequences, particularly when there isn’t a temporal contingency between the behavior and its consequence or when the consequence of a behavior is the avoidance of an untoward outcome such as illness. The research literature suggests it is

possible that cognitive development and experience with illness play crucial roles as setting conditions for health-promoting behaviors in children, but how or even if it works as we have suggested with the ABC model is not known.

So where does all of this discussion about the ABCs of behavior lead us in understanding the development of health-promoting behaviors? On the one hand, it provides a general framework for systematically analyzing and understanding behavior. It directs us to consider the antecedents and consequences involved in the acquisition and maintenance of health-promoting behaviors over time, and to focus on the fact that not all antecedents and consequences act with equal power in controlling behavior. There are likely to be individual as well as group differences in their selective abilities to initiate and maintain behavior. Further, it is clear that the consequences of compliance or non-compliance with health-promoting behavioral regimens are not immediately apparent to the individual. In short, it seems that there is much to be learned about the antecedents and consequences of health-promoting behavior not only in children, but also in adults. For example, our research agenda should include studies on the roles of contingency or stimulus relevance principles in the acquisition and maintenance of health-promoting behaviors during childhood. Questions addressing the nature of the antecedents or effective controlling consequences, the ideal conditions for introducing health-promoting behaviors, the effects of chronic diseases and conditions on the antecedents or specific consequences, the impact of chronic diseases and conditions on the timing of consequences in controlling behavior, and many others like these would not necessarily emerge unless we use an approach similar to the ABC model suggested here.

### **Family role in shaping health-promoting behaviors**

It is likely, but not empirically verified at this time, that the initial acquisition of hand washing and tooth brushing is tied to the child’s desire to obtain parental (or caretaker) approval by modeling their behavior. While this may be the single most important factor in the initial acquisition and maintenance of these behaviors, given the vagaries of adolescence, it is unlikely to be the mechanism by which these health-promoting behaviors survive to adulthood. And it is even less clear why adults adopt or continue these behaviors. A famous behavioral scientist has observed that it is as if early in life the child is saying, “I want to be like my parent at any cost.” Then comes adolescence, during which the teen seems to be saying, “I want to be like anyone but my parent at any cost.” And finally, we reach adulthood when the person says with shock and dismay, “Oh my goodness, I **am** my parent...and it costs.”

An excellent summary of research on the influence of families on oral health by Inglehart and Tedesco points to several ways in which families influence health-promoting behavior.<sup>2</sup> Families can influence affective reactions toward dental health by instilling fear or acceptance of the dentist in children. A child who learns to fear dental procedures may be less likely to engage in oral health-promoting behaviors, including an annual visit to the dentist.

Another major influence of families on oral health-promoting behavior is through health beliefs, such as a generally positive attitude toward engaging in health-promoting activities. Health beliefs develop early in life and by the early teens an individual has a fairly stable set of health beliefs. There seems to be a mutual reinforcement of health beliefs among family members that facilitates the development and maintenance of a consistent constellation of behaviors within the family unit. To the extent that these behaviors are acquired early enough in life and provide the foundation for other health-promoting behaviors, the family can play a key role in an individual's adult health.

### Early experience and later health behaviors

Do health-promoting experiences occurring in childhood provide a substrate upon which adult health-promoting behaviors are built? And if they do, are there some that are more important than others in building the foundation? Could it be that the major developmental task is to instill positive attitudes toward health promotion that can be carried into adulthood and facilitate the acquisition of health-promoting behaviors?

It seems reasonable to assume that children with early experiences involving health promotion training should, as adults, be more inclined to exhibit health promotion activities. Hertzman and Power and Hertzman show that early life factors can be linked to adult health status through various biological and sociological pathways.<sup>7,8</sup> These studies, while not specifically testing the relationship between health-promoting behaviors acquired in childhood and those exhibited during adulthood, seem to provide at least presumptive support for such a connection. Unfortunately, there are no data that specifically address this connection.

The closest we can come are data from studies on adults that looked for connections between various health-promoting behaviors by asking whether people who engage in one specific behavior also engage in others. For example, Harris and Guten's early study on health-protective behaviors in adults revealed several clusters of health behaviors.<sup>4</sup> While behaviors within a cluster represent a group of related behaviors, various clusters appear to be independent of each other. Similar subse-

quent findings have been reported by Tapp and Goldenthal, Norman, and Kronenfeld, et al.<sup>9,10,11</sup> More recently, Sobal, et al. identified 10 independent dimensions underlying health-promoting behaviors.<sup>12</sup> They conclude that "engaging in one health behavior is not necessarily associated with practicing others.... Efforts to encourage healthy behaviors should be multifaceted and behavior-specific." The findings that there is little or no connection between various health-promoting behaviors for adults (within an age stratum) would seem to dictate against the possibility that there might be such a connection between childhood and adulthood (between age strata).

As mentioned, the acquisition of early health-promoting behaviors could have an impact on adult attitudes rather than specific behaviors. That is to say, it is possible that children who learn to wash their hands and brush their teeth acquire a positive general attitude toward health-promoting behaviors, and as adults, are more likely to engage in health-promoting behaviors. Suggestive evidence in support of this notion comes from a study by Glik, et al. in which 398 adults were queried about what they do to stay healthy.<sup>13</sup> Their findings show that a person's attitudes about which behaviors are important to maintain health or a healthy lifestyle are more important in determining the actual health-promoting behaviors in which he or she engages than the individual's position or role in relevant social groups. These findings, of course, are only suggestive and do not address the question about building positive attitudes toward health-promoting behaviors in children through early training.

None of the studies cited above included children as participants, and none were longitudinal, limiting our ability to examine connections between health-promoting behaviors acquired in childhood and those exhibited in adulthood. None of the studies provide clues as to which, if any, early experiences lead to adult health-promoting behaviors. Nor is there any research that provides clues about the behavioral mechanisms by which these early experiences might influence adult health-promoting behaviors. And further, there is no research that indicates the impact of this entire process on health status *per se* at any point in an individual's life. Nevertheless, it would seem safe to hypothesize that the most likely connection is not between specific childhood behaviors and adult health-promoting practices but that adult behaviors can be mediated through positive attitudes toward health-promoting practices developed in childhood. It would seem worthwhile to test this hypothesis with longitudinal studies involving children looking at the same or similar behaviors at several points in time. Once the connection is understood, the next step would be to determine

whether children with disabilities exhibit a pattern different from children without disabilities.

### A child's view of health and illness

The ABC model focuses primarily on external events such as setting conditions, behaviors, and outcomes of behavior, and internal events such as cognition are not part of the model. Research involving the child's view of illness points to the potential importance of the level of cognitive functioning and the child's knowledge of the causes of illness in the development of health-promoting behaviors. Research by Charles Kalish and his colleagues, among others, would seem to be relevant.<sup>14,15</sup> They have shown that pre-school children tend to be deterministic thinkers about the causes of illness; children judge that all members of a group will respond in the same way to a potential cause of illness, while adults understand that there are many causes of illness and whether an individual becomes ill at any given time follows probabilistic rules.

The reasons for children's reliance on a deterministic model of illness are not yet fully understood. One possibility is that they may not realize that illness takes time to develop, or they may have not yet developed a full understanding of the germ theory of disease. Third, they may not have the experience to understand contextual conditions such as stress may contribute to why only some people exposed to the same germs will get sick. And finally, recent research by Bases indicates that what children reveal about their knowledge of illness is greatly influenced by the types and wording of the questions we ask them.<sup>16</sup> Children's responses are significantly modified depending on slight wording changes in questions and the format of the questionnaire (i.e., agree/disagree v. multiple choice).

The differences between a child's and adult's concept of illness can be understood within the framework of Piaget's theory of cognitive development (as reviewed in Schonfeld).<sup>17</sup> There is a systematic and predictable sequence by which children acquire an understanding of the concepts of physical illness, and the process is comparable to acquisition of causal understanding as described by Piaget. Likewise, there may also be systematic and predictable changes in their understanding of health-promoting behavior. Postulating changes in cognitive functioning is certainly consistent with findings from research on locus of control (e.g., Rotter) and research assessing the impact of educational programs on the child's understanding of the causes of AIDS and cancer.<sup>5</sup>

Piaget held that a child progresses through four distinctly identifiable sequential states of cognitive development: *the sensorimotor period* (0 – 2 years) when the

child's sensory and motor systems are developing and during which he or she is acquiring information about his or her universe; *the preoperational period* (2 – 7 years) during which the child develops mental imagery and language but still relies on direct personal experiences and has limited ability to generalize; *the concrete operational period* (approximately 7 to 11 years) during which the child begins to see a situation from another perspective but is limited in the ability to perform abstract operations; and *the formal operational period* (11 years through adulthood) characterized by abstract thought and reasoning.

Schonfeld summarizes the development of a child's understanding of the causes of illness as starting from magical thinking and a notion of imminent justice, a system in which misdeeds are punished with illness and good ones rewarded with health.<sup>17</sup> As a child's experience with illness increases, presumably through a combination of firsthand experiences with acute or chronic conditions or with increasing cognitive development, the link between illness and misbehavior are replaced with perceptions of personal control over illness and recovery. Some research has shown imminent justice is replaced by more appropriate explanations of illness when the child is personally familiar with the illness as in the case of colds.<sup>18</sup>

Once a child develops an accurate concept of the true causes of illness, he or she then begins to understand the concept of contagion. Here children in the preoperational stage tend to think of all diseases as contagious, while older children distinguish contagious diseases from non-contagious ones; in a Siegal study, however, preschoolers were able to differentiate between diseases that were contagious, such as colds, from and those that were not, such as scraped knees.<sup>18</sup> Along with the ability to know the difference between contagious diseases and non-contagious ones is an understanding, at some level, of a germ theory of disease. This finding has important implications for development of age-appropriate health educational materials that incorporate information requiring a causal understanding even in preschoolers. In fact, much of Schonfeld's research has been about designing and testing programs aimed at teaching children in grades K-6 about AIDS.<sup>19,20,21,22</sup> He and his colleagues have found that a "conceptual understanding about AIDS can be achieved *in very young children* (italics mine) through direct educational interventions" aimed at advancing factual knowledge about AIDS and decreasing misconceptions about casual contact as a means of acquiring the disease. His research, along with that by others, has not addressed the impact of a cultural, ethnic, or gender overlay to these specific developmental sequences.

## Pathways between early health promotion and adult health: Can we get there from here?

We have already alluded to the need for research elucidating the mechanisms involved in translating the childhood health promotion experiences and knowledge to adulthood. It would seem reasonable to assume that the development of internalized locus of control would play a major role in the process of getting from early health-promoting behaviors to those expressed in adulthood.<sup>5</sup> Unfortunately, there is no research confirming or refuting this speculation. There is, however, an emerging research literature on the relationship between early life factors and adult health. This research examines the sources of disparities in adult health, including those relating to socioeconomic status, and may provide a framework within which health promotion behavior can be studied. Results from these studies may be helpful to us in terms of learning about how health-promoting behavioral patterns formed early in life become part of adult behavior, but also in terms of potential theoretical models around which research can be organized.

Three models have been proposed to account for the connection.<sup>7,8</sup> The first is the *latency or critical period model* in which the early life environment affects adult health independently of intervening experience. Examples of the latency effects are seen in studies that show associations between birthweight, placenta size, and weight gain in the first year of life with cardiovascular disease when the individual reaches his or her fifties. From this perspective, adult disease is in a sense “programmed” during fetal life and infancy. Adding credibility to this model is the knowledge from the study of human and animal development that there are well-defined critical periods for development of many skills, including language and other cognitive capacities.

The second is referred to as the *pathways model*. This model views the effect of events during early development as setting the individual on a life-long developmental trajectory leading to adult health differences. The model focuses on the cumulative effects of life events along the trajectory and in some sense incorporates elements of the latency model insofar as a specific trajectory can be viewed as a series of discrete events that accumulate over time. It relies heavily on the assumption that health status at any point in time results from the specific series of twists and turns taken along the trajectory. Strongest support for this model comes from research that shows the enduring effects of socioeconomic status on health.

The third model views the *cumulative effects* of influences over time. From this perspective, it is the accumu-

lation of advantage or disadvantage over time, based on the duration and intensity of factors that have the potential to confer health or disease in adulthood. For example, as noted by Hertzman, the cumulative effect of income is suggested from research that shows that the association between adult health and income becomes stronger for earnings accumulated over several years than for any single year.<sup>7</sup>

It is important to note that the three models are not necessarily mutually exclusive and that one model may work best in explaining the relationship between one particular factor and adult health than the others. As noted by Hertzman, a major birth cohort study conducted in Britain confirmed cumulative and trajectory effects on self-rated health for socioeconomic condition between birth and 33 years of age.<sup>7</sup> Latent effects were also found for self-rated health at 33 years of age using the variable “parents read to child at age 7,” even after educational attainment had been controlled. Another latent effect for self-reported health was reported for percent of adult height at age 7. With these three models, we have a potentially fruitful point from which to start in our study of pathways or mechanisms by which early health-promoting knowledge and behavior translates into health-promoting behaviors for the adult.

### Needs and opportunities: research questions

There are great needs and many opportunities for research on the development of health-promoting behaviors. A central question is to understand why, under a given set of conditions, some people adopt health-promoting behaviors and others don’t? A corollary of this question is to understand why an individual changes his or her strategy and either begins to engage in health-promoting behavior or decides to stop? Using a particular model of studying behavior along with research and concepts available from what is known about a child’s knowledge of disease and illness, we have tried to identify some of the factors that might be important in studying the development of health-promoting behaviors. Some important research areas that should be addressed include studies of:

Foundations for health-promoting behaviors throughout life:

- What, if any, are the behavioral foundations laid down in childhood—such as health self-efficacy and internalized locus of control—upon which health-promoting behaviors exhibited in adults are built?
- Are there specific behaviors or experiences in childhood, such as hand washing or tooth brushing, that become health-promoting behaviors in adulthood or is the connection more general?

- What impact does a chronic condition or disease in childhood have on the process? What impact does culture, ethnicity, or gender have on the process? How do these factors interact with chronic childhood conditions or diseases?

Acquisition and maintenance of health-promoting behaviors in childhood:

- What are the “rules”—including stimulus relevance, modeling, and contingency—for the acquisition and maintenance of health-promoting behaviors in childhood? What are the effective setting conditions and motivators? What are the effective consequences? How do chronic childhood conditions or disease affect setting conditions or consequences?
- Is there a critical period for the acquisition of health-promoting behaviors beyond which it is difficult or impossible to effectively introduce these behaviors?
- What are the most effective didactic approaches to early childhood health promotion education? What are the roles of various setting conditions—such as culture, ethnicity, chronic conditions and diseases, gender—in designing these approaches?
- What is the role of a child’s cognitive development or understanding of illness in adopting health-promoting behaviors?

Pathways between childhood and adult health-promoting behaviors:

- Are there behavioral mechanisms that link childhood health-promoting behaviors with those in adulthood?
- What models (critical period v. trajectory model) can best account for any links between childhood and adult health-promoting behaviors?

In addition, we have noted several methodological issues, such as the need for longitudinal studies throughout the life span and the need for qualitative as well as quantitative research in addressing real world questions about the role of health promotion behaviors in health.

### Final thoughts

Throughout this paper, we have made the assumption that a developmental approach in understanding health-promoting behaviors is the most appropriate and fruitful one. A longitudinal approach not only provides information about the origins of behavior at any point in time, but it also helps explain and understand individual differences in the expression of behavior. And our limited understanding of the acquisition and maintenance

of health-promoting behaviors in children extends to what amounts to a total lack of information about variations in their expression. It would seem to be a mistake to assume that what we know about adult health-promoting behaviors is directly applicable to the same or similar behaviors in children. It is important to remember that children are not small adults and, similarly, that children with chronic inherited, congenital, or environmentally induced conditions may not be simply normal children with an illness.

Another corollary is that children from various ethnic, racial, cultural, or economic backgrounds aren’t simply white middle-class children with a different skin color, language, or cultural background or with less money to spend. And, finally, we must always be aware of the likelihood that gender differences can exist throughout development.

This complexity requires us to include variables relating to these factors in our research. Further, in designing educational materials or programs, we need to factor in ethnic, cultural, or gender-based differences in learning styles, expression of behaviors, and responsiveness to various consequences and conditions. Consider, for example, the development of materials used to inform people about the importance of using seat belts to prevent injuries as the result of car accidents. Dr. Roberta Baer (personal communication), an anthropologist, notes that the same message found to be effective for white middle-class individuals was totally ineffective for migrant farm workers. Migrant farm workers are much more tuned to issues of immediate and present importance and less so to issues of the future possibilities. Thus, messages about preventing injury in some indefinite future accident were less effective in getting adults from this community to use seat belts consistently than messages that addressed the immediate responsibilities of the parents for the safety of their children.

The implications of this kind of research are important and far-reaching. For example, it is not enough to translate materials from English to Spanish or Haitian or to any other language or dialect in order to develop a message that is appropriate and effective for individuals from multiple and diverse groups. One must also take into account age, gender, and culturally appropriate variables as well as factor in antecedent conditions, behaviors, and consequences appropriate to the learning styles and physical functioning of the children for whom the health-promoting behavior intervention is designed. Finally, these issues need to be addressed in designing appropriate and meaningful assessments of the impact of early health-promoting behaviors throughout life.

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# Oral Health-promoting Behaviors

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Although children with special health care needs represent about 20% of the pediatric population, very little research has been done on oral health-promoting behaviors that affect these children. According to the Bureau of Maternal and Child Health,<sup>1</sup> children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. With reference to typical children, these children are considered to have special health care needs for one of three reasons: they require more frequent health care, they require more specialized health care, or they require alternate health care.

Dental care is the most prevalent unmet health need among this group of children. This paper will use data from both parents and children to illustrate outstanding significant oral health issues of this population.

## Defining special health care needs in terms of dental care

Children with special health care needs have physical, emotional, and cognitive conditions that affect their health or their ability to receive medical or dental treatment.<sup>2</sup>

Physical conditions may affect access to the dental office, the treatment itself, or home care practices. It may be difficult to transport children with physical impairments to the office itself, especially if the dentist willing to treat children with special health care needs is not local. Getting into the office can also be a challenge, as not all dental offices are set up for special access. These children may have trouble getting into the dental chair and may need a dentist experienced in treating children who are confined to a wheelchair. Physical conditions may also affect a child's ability to participate and cooperate in dental treatment. Some of these children may not be able to open their mouths on command, open them at all, or keep them open. Others may have difficulty because of tactile sensitivity. These children may also face challenges when practicing home care. Children of all ages lacking fine and gross motor control may find it difficult or impossible to brush and floss adequately.

Emotional conditions can present as much of a challenge to dental care as physical ones. Emotional difficulties may include fear of the dentist, dental treatment, or any interventions involving the mouth. Many children with special health care needs may be predisposed to fears of the dentist or dental treatment due to unfavorable past experiences. As with typical children, children with

special health care needs may struggle with dental pain. Problems may be exacerbated by feelings about one's facial difference or speech.<sup>3</sup>

Cognitive conditions may affect a child's developmental age and therefore his or her ability to understand situations in the dental office and home care issues. In fact, research has shown that explanations and information that reduce fear and anxiety in typical children may actually increase fear and anxiety in children with developmental disabilities.<sup>4</sup> Cognitive conditions include mental retardation, learning disabilities, and attention-deficit hyperactivity disorder. These disabilities may make it difficult for the child to understand the dentist's requests during the visit, the purpose of the dental treatment, and the importance of and instructions for home care.

The development of oral health-promoting behaviors is not well understood in children with special health care needs, or in children in general. Four variables are involved: the child, the parent, the practitioner, and the service system.

## The child and oral health-promoting behaviors

The child's role in oral health-promoting behaviors primarily involves cooperating with the dentist, as well as practicing or cooperating with home care. Although all the factors involved in developing oral health-promoting behaviors are not known, it is suspected that children's knowledge and understanding plays a very important role—specifically, knowledge and understanding of oral diseases, their causes, and prevention.

Recently, I surveyed parents of children with chronic conditions or disabilities in order to find out more about oral health-promoting behaviors and barriers to care. These parents were drawn from the 100 ethnically diverse parents living in central Los Angeles who had originally participated in the Lanterman Study (a survey conducted by the University Affiliated Program of the University of Southern California) to look at primary and preventive care for children with developmental disabilities between the ages of 4 and 17.<sup>5</sup> Parents were asked:

- 1) Does/would your child have difficulty understanding the dentist's requests during the dental visit?
- 2) Does/would your child have difficulty understanding the purpose of the dental visit/treatment?
- 3) Does/would your child have difficulty understanding the purpose/instructions for home care?

About half of the parents responded affirmatively to these questions, confirming the presence of problems in children's understanding of treatment issues. We assume

that younger children and children with more cognitive developmental issues may have less knowledge and more trouble understanding.

Valuing children's understanding of oral health is important for many reasons. Recently, child health care practitioners have emphasized the right of children to be informed about their medical conditions and treatment and to be involved in decisions pertaining to care.<sup>6</sup> A better understanding of young children's knowledge and reaction to dental care can guide professionals in discussing dental treatment and involving children in decisions about their health care in developmentally-appropriate ways. Such knowledge provides insights about the psychosocial effects of different treatment options for children of different cognitive levels, aids in the development of methods to reduce children's fears and misconceptions regarding treatment, and may even suggest strategies for improving compliance to treatment and home care instructions.<sup>7</sup>

I have also been examining children's understanding of their craniofacial conditions (CFCs) to increase understanding of the impact of CFCs on childhood development and behavior. Although CFCs such as cleft lip and palate represent one of the most frequent types of human birth defects and chronic childhood conditions, very little research has been done regarding what children younger than 8 years old understand about it.

It has been widely documented that conditions such as cleft lip and palate can significantly affect general quality of life<sup>8</sup> as well as health-related quality of life.<sup>9</sup> CFCs involve all three areas noted by Atchison<sup>10</sup> to be important to the assessment of oral health: physical function (which includes eating and speech); psychosocial function (which includes dissatisfaction with appearance and social avoidance); and pain or discomfort. Because children can be aware of their conditions and treatment at very young ages, the type of knowledge and understanding that a young child has of his or her condition and treatment deserves attention.

Researchers in developmental psychology, education, and medicine have all investigated children's understanding of illness. Developmental psychologists have attempted to understand what children believe at different stages of development. Educators have been interested in learning how best to teach health education at various ages. Medical professionals, including dentists and pediatricians, have tried to use this information in order to explain conditions to children, promote child compliance to treatment, and involve children in the decision-making process.

Much of the early literature on how children develop an understanding of health and illness was strongly

influenced by Piaget.<sup>11</sup> This literature was based on a belief that young children can only minimally understand concepts of health and disease.<sup>6</sup> For example, Bibace and Walsh<sup>12,13</sup> developed a theory of children's understanding of illness based on Piagetian stages of cognitive development. Their purpose was to create a guide for practitioners regarding the level of explanation appropriate for children of different ages. The data suggested that children's understanding of illness parallels the cognitive developmental stages of preoperational (age 4-6), concrete operational (age 7-10), and formal operational (age 11 and older) thinking. With increasing age, a child distinguishes internal and external parts of the body and becomes aware that other people have illnesses that differ from their own. This differentiation is also manifested in an increasing sense of control and responsibility.

More recent research challenges the assumption that cognitive immaturity inevitably leads to children's misconceptions and partial understanding of illness. For example, Carey<sup>14</sup> argues that the ways in which children and adults come to understand new concepts is fundamentally the same. Instead of cognitive limitations *per se*, it is a lack of information that keeps preschool children from having sophisticated understanding of concepts of illness. Indeed, Kister and Patterson<sup>15</sup> investigated young children's typical explanations of illness causality with the use of imminent justice, a belief that illness is a form of punishment for misbehavior. They concluded that those children who had more information regarding illness causality, regardless of age, used imminent justice much less often. The clinical significance of Carey's research is that, although children may not yet have a mature understanding of illness, if provided useful information, their knowledge and participation in treatment decisions can be expanded. Such explanations may help eliminate the child's experience of guilt, and reduce fear and expectation of punishment, thereby improving their cooperation with treatment.

Using these two, somewhat contrasting perspectives of Piaget and Carey as background, several studies have addressed what healthy children understand about illness. These studies found that their explanations correlated well with Piaget's<sup>11</sup> stages of cognitive development.<sup>6,12,13</sup> Potter and Roberts<sup>16</sup> studied children ages 5 to 9 years and concluded that subjects who did not receive additional illness information perceived themselves as more vulnerable than the group who did. Moreover, younger children sometimes assumed they could catch a condition that was not contagious (diabetes, epilepsy) from peers. Therefore, children may be avoided by peers who fear that their condition is contagious, particularly children of younger ages.

Charman and Chandiramani<sup>7</sup> studied children ages 5, 7, and 9 to determine their understanding of chicken pox, an illness familiar to many children of these ages, and depression, a less obvious illness. Children of all ages showed a basic knowledge of both conditions. Many children mentioned appropriate objective signs, and objective and non-observable symptoms of both chicken pox and depression. Fifty percent of the five-year-olds suggested appropriate strategies to prevent chicken pox and 76% of them suggested appropriate strategies for preventing depression. Ninety-two percent of subjects appropriately mentioned life events as possible causes of depression and 85% of subjects correctly mentioned contagion as a possible cause of chicken pox. The researchers concluded that, although information and cognitive level contributed to more sophisticated responses, all children had at least a basic knowledge of illness.

It is important to investigate specifically children with craniofacial conditions rather than to generalize findings from studies of well children or children with other conditions. First, children with chronic conditions may have completely different perceptions of illness than other children.<sup>17</sup> As Minde, Hackett, Killou, and Silver<sup>18</sup> point out, there may be a difference between what well children understand about illness and what children with a specific diagnosis understand about their own condition. They found that between the ages of 5 and 9, children with a chronic condition experience unique events triggered by both the loss of their peer group and the exposure to other children with chronic conditions. These children first cognitively realize that their condition will not disappear, go through a depressed period, and then begin to see the condition as part of their identity. Additionally, in the specific case of children with CFCs, because there is a concrete aesthetic

aspect to a craniofacial condition, it is possible that young children who lack the ability for abstract thinking understand even more than what is reported by studies of children with less physical evidence to their conditions.

Although few studies have been published on young CFC children, studies indicate that even young children seem aware of their disabilities. Dunn, McCartan, and Fuqua<sup>19</sup> investigated whether young children know that they're different from typical children and whether young children know that they actually have a disability. They studied children ages 3 to 6 years and found that a third of the children knew they were different, 50% knew they had a handicap, and 86% knew the name of their disability. Half of the children knew of the permanence of their disability, whereas only a small percent knew that they were born with it. Half of the children thought that their disability would disappear when they were older and they would, for example, be able to run better. Often children understood they were different before they understood their disability. Therefore, although it is likely that even young children recognize that they have a craniofacial condition, these children very often lack appropriate knowledge about it. How children gather information and perceptions about their CFCs is important in terms of educating children about their conditions. Because children are capable of understanding when given appropriate explanations, it is in part the responsibility of orthodontists and other clinicians to convey these explanations.

The following tables present data obtained from 10 children with CFCs (unpublished manuscript): These children were interviewed to get a sense of the kind of responses that children at different developmental stages might make to questions about their condition.

**Table 1—Sample description**

Child	Gender	Ethnicity	Age	Age Group
1	M	Caucasian	3y 9m	Younger
2	M	Asian American	4y 3m	Younger
3	F	Hispanic	5y 8m	Younger
4	F	Caucasian	6y 11m	Younger
5	M	Hispanic	8y 2m	Older
6	F	Caucasian	8y 2m	Older
7	M	Hispanic	9y 0m	Older
8	F	Caucasian	9y 3m	Older
9	F	Asian American	9y 3m	Older
10	F	Native American	10y 10m	Older

This sample has been recruited from the Craniofacial Clinic at UCLA. The table indicates that the population includes a wide ethnic diversity and that even young children are able to participate.

I plan to develop a structured interview to understand the CFC child's perception of his/her condition and its impact on his/her quality of life. The methodology involves a structured interview process that has enabled me to interview children to gain a better understanding of the child's perception of their condition and its impact on QOL. It appears that the development of the ability to make cause-and-effect linkages may account for some differences between younger children, ages 4-6 years, and older children, ages 8-10 years. In the area of condition perception, I have found that development may occur in two stages: awareness of condition and understanding of treatment. All children in the sample are undoubtedly aware of at least the fact that there is an atypical scar on their face and also that they come to the clinic to see doctors for help. But although younger children do perceive their condition, only older children can report that their condition makes them different in some way from most children and that the purpose of coming to the clinic is to help correct/improve issues related to this condition. When asked, "Why do you come to this clinic?" and "Is anything different about your face from other children?" younger children seem unable to make the appropriate link between the purpose of a clinic visit and the presence of an atypical condition, as shown in Table 2.

In the area of quality of life, my data also reveal that the development of the ability to make cause-and-effect linkages may explain the knowledge limitations demonstrated by the younger children. The children's responses indicate that physical limitations affect children's psychosocial functioning. All four boys who responded to our survey answered affirmatively to the

question, "Do you have any trouble speaking well?" but only the two older boys reported that they have social trouble because of it, as shown in Table 3.

Investigating what children know and can understand about their conditions and disabilities can help optimize the care and quality of life of children and their families. Insight into these issues allows for better intervention by clinicians. Knowledge regarding what children understand about their conditions and their treatment will help dentists and pediatricians discuss medical procedures with young patients. Improved discussions between doctors and patients increases patients' ability for informed consent and may also increase treatment compliance.

### The parent and oral health-promoting behaviors

The oral health-promoting behaviors of parents, in addition to those of the child, are central to the oral health care of children with special health care needs. The parent must work with all three of the other players—child, practitioner, and service system—in order to be able to practice oral health-promoting behaviors. Aside from financial constraints, lack of understanding, time, or motivation may explain why some children with special health care needs do not receive enough dental care. Parents of children with disabilities may not be motivated to put time and effort into their child's dental needs in the midst of dealing with the many other appointments and practitioners necessary for their child.<sup>20</sup> It is the parents' behaviors that are necessary to link the child with the practitioner and with the service system.

**Table 2—Children's responses to survey questions, by age group**

Age Group	"Why do you come to this clinic?"	"Is anything different about your face from other children?"
Younger	The doctors fix me.	Nothing.
	To see the doctors, so they can fix me.	My eyes are different, dark brown.
Older	To check and see what they have to do for my surgery so they can close my gum.	Yes, it's not the same. They have a straight nose and I have a crooked nose.
	To get surgery...to help my nose... 'cause it's funny.	All of us have different faces and stuff...some kids might have stuff...like something that isn't supposed to be fixed.
	Because I get my palate fixed.	My lip.
	Check-ups, braces, bone scan.	My teeth are crooked and up in my mouth; I'm missing a piece of bone.

**Table 3—Boys’ responses to survey speech questions, by age group**

Age Group	How much [trouble speaking well]?	What do you mean?	Do you have any difficulty at school because of the way you speak?	What do you do to make it easier?
Younger	A lot of trouble	I have to go to the doctor	No	N/A
	A lot	I talk to teachers	No	Because I like to have fun.
Older	A little bit	My e’s, I can’t say them right.	Yes	I don’t talk...to other kids...sometimes I do, when the teacher calls on me.
	A lot	When I say something I can’t say it right.	Yes	Talk less. I don’t talk a lot because I don’t want to talk a lot and I have a lot of trouble.

On one level, the parents’ interactions with the child promote oral health; these behaviors include prioritizing the child’s dental care as a necessity, transporting the child to the dental office or arranging for assistance in order to do this (which can be especially complicated in the case of a child with a physical disability), and practicing daily home care with the child. The parent must also interact with the practitioner in order to practice behaviors that optimize oral health care for the child. This involves finding a practitioner who is willing to treat the child, educating the practitioner on physical, emotional, or cognitive issues of the child, discussing treatment options with the practitioner, and finding a practitioner who is willing to accept the form of payment. Finally, the parents’ behaviors involving the service system also determine oral health care for their child with special health care needs; this mainly means figuring out how to pay for the child’s dental care.

Because the parents’ oral health-promoting behaviors serve as the link between the child and optimal oral health care, the parents’ behaviors are critical in determining the quality of care that the child receives. Because parents of children with certain disabilities often experience higher levels of stress,<sup>21</sup> these parents may be less able to coordinate their child’s oral health care needs. About half of the parents of children with chronic conditions that I surveyed from the Lanterman Study had a disability themselves; half mentioned that their child has not been visiting the dentist regularly because oral health care needs have been difficult to prioritize among all the other special needs of the child; and half mentioned that they have not visited a dentist regularly themselves because of a lack of money.

A child’s chronic condition or disability produces a significant amount of stress for both the individual and the family.<sup>22</sup> Pediatric chronic physical disorders are considered to be a chronic strain for both the children and their parents.<sup>23,24,25</sup> Bell’s interactional mode<sup>26</sup> has led researchers to investigate the ways that the environment (peers, parents, etc.) affects the child and the ways that the child affects the environment. Specifically, the behavioral adjustment of a child is both affected by, and has an effect on, parents.

Research has focused on what parents of atypical children experience. Many experts believe parents experience an initial period of mourning upon the birth of an atypical child.<sup>27,28</sup> It is even thought that some families never fully recover from the birth of an abnormal child.<sup>29</sup> Factors that may affect parental stress may include socioeconomic variables, the level of support from family and friends, the number of surgeries and amount of medical care their child requires, the extent of anomalous functional capacity, and the appearance of the child.

### **The practitioner and oral health-promoting behaviors**

Every parent of children with special health care needs I surveyed spoke of difficulty finding a dentist in the area willing to treat his or her child, and every one of these parents asked me for a referral to a dentist in their area who treats children with special needs. The practitioner involved in the oral health of children with special health care needs is mainly the dentist, but the roles of the pediatrician and others involved in the child’s health care often can be of equal importance. These profession-

als must work together to promote the oral health of children in general, and that of children with special health care needs specifically.<sup>30</sup>

Because a pediatrician is typically seen earlier than a dentist for health care, pediatricians are in a good position to make referrals for dental visits. Thus, it is especially necessary for pediatricians to be able to recognize when a child should see a dentist. Recently, I called around informally and asked 16 pediatricians when they believe a child first needs to see a dentist. The American Academy of Pediatric Dentistry states that this visit should occur by the first birthday or when the first tooth appears. According to the 16 pediatricians I spoke with, it is somewhere between when children get their first teeth and when they get their first adult teeth.

In addition to the need for qualified and willing practitioners to treat children with special health care needs, physical access to these practitioners is another problem with the system. These practitioners are few and far between, often requiring extensive travel and planning in order for the child to have an appointment. Accessing willing and qualified dental practitioners to treat children with special health care needs and paying for the services needed are among the greatest barriers to adequate dental care for these children. Practitioners often are not willing both because they were not trained to treat children with special needs and because they do not get adequately reimbursed.<sup>31</sup>

### **The service system and oral health promotion**

In my recent survey of parents of children with special health care needs, I asked the question, “Has your insurance coverage been unfair/inadequate?” One parent reported that her daughter has been in a baby crib for 12 years because she can’t get the special bed that her daughter needs; this mother was able to get the special crib when she had Blue Cross when she was working as a teacher. However, she has had to stop working to take care of her daughter, who is paralyzed, has brain damage, and can only speak a few words. She now relies on MediCal coverage. A mother of two children with disabilities explained to me how she has been fighting for orthodontic coverage to help her autistic son’s speech difficulties; MediCal won’t pay for braces until age 14, and the orthodontist and speech therapist said that it is counterproductive to train his speech now with therapy and then, in a few years, change his teeth with braces.

Payment methods for care for children with special health care needs include out-of-pocket-payments, private insurance, and public assistance. Few families can afford to meet the cost of the extensive treatments often required by children with special health care

needs. Therefore, they must resort to private insurance or public assistance. Those with private insurance may not only find that their coverage is limited in general but that the rules are irrelevant when it comes to children with special health care needs. Many private insurance companies do not extend coverage or include any exceptions for these children. They are designed to help pay for the care of typical children.

Dental treatment for children with special health care needs in the state of California may be covered by either MediCal, or California Children’s Services (CCS). CCS will help pay for health needs for qualifying children with medical conditions. MediCal will cover dental care for children with special needs, plus care for cleft lip, cleft palate, or other facial problems. Although these sources of public assistance also have limitations in terms of what they will cover, the greatest problem seems to be in finding available, skilled providers who will accept this type of coverage. Often, families will have to travel far to find a practitioner who accepts MediCal or CCS coverage. Frequently, families will find that new practitioners who have not yet built up their practices will be more likely to accept these sources of payment, although they may not have any training or experience in treating children with special health care needs.

### **Needed benefits and services**

The development of the behaviors necessary to promote oral health for children with special health care needs starts with educating all four players: the child, the parent, the practitioner, and the service system. Educating children will help them understand their oral health needs, the reasons for cooperating with the dentist, and how to practice home care. Educating parents, practitioners, and service systems will help them understand children and what children with special needs require.

Although the preventive, restorative, and emergency dental care needed by all children are applicable to this special population, additional care in these areas and in the rehabilitative category may also be needed. For example, physical, emotional, or cognitive conditions may make it more difficult for children to receive adequate home care. Children who have difficulty practicing or cooperating with home care, or who are more susceptible to dental and periodontal decay, may benefit from more frequent, intense preventive care. Moreover, restorative and emergency care may be needed more frequently in these children. Finally, children with congenitally atypical or missing oral structures or function may be in need of rehabilitative care that typical children usually do not need.<sup>32</sup> For example, periodontal disease is often an issue for

children with disabilities, but in general, is rarely addressed for children as typical children do not incur periodontal problems.

Not only do the conditions of children with special health care needs require definition, but plans to identify, treat, and pay for the specific dental needs of these children must be developed. Parents need to be informed primarily on the need for preventive care. Preventive care must be addressed as early as possible, before the problems start; therefore, parents should be educated on the preventive dental needs of their child by pediatricians and other practitioners seen by the child even before they ever reach the dental practitioners.<sup>30</sup> Other practitioners also need to be educated on what the possible dental issues are that children with special health care needs may face.

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# Nutrition and Oral Health

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Nutritional status and oral health are closely associated in children with neurodevelopmental disabilities, those with craniofacial malformations, metabolic disorders, or those born prematurely.<sup>1,2</sup> Special needs children are especially susceptible to oral infections such as oral candidiasis, viral infections, dental caries, and periodontal disease. The quality of the diet and eating patterns may influence a child's susceptibility to these oral diseases. Feeding problems of special needs children may affect oral health (Table 1). Oral hypersensitivity, sucking, chewing, and/or swallowing problems, drug-nutrient interactions, tongue thrust, and poor muscle tone may interfere with the desire and ability to eat, thereby making it difficult to meet nutrient needs. Developmental dental enamel defects may result from a nutritional insult during pregnancy or early childhood. These structural defects may increase caries risk. Daily use of multiple medications can compromise oral and nutritional status.

Diet plays a pivotal role in the development of dental caries. Inappropriate use of the nursing bottle, frequent snacking on retentive sweet foods, or chronic use of sucrose-based medications greatly increases the risk of dental caries. Children with neurological impairments such as cerebral palsy often require prolonged feeding times to obtain adequate calories. This provides an extended opportunity for acid production in the mouth. An additional concern is dental enamel erosion caused by gastroesophageal reflux. Dental providers and educators who work with children with special health needs are in ideal positions to provide early preventive nutrition counseling that will enhance oral health. This paper will focus on dietary habits that affect children's oral health status. It will also provide guidelines for early nutrition intervention that will lower the risk of oral disease in children with developmental disabilities.

## Development of oral structures

There is emerging evidence that early malnutrition affects tooth development and eruption and results in increased dental caries in the primary teeth (Table 2).<sup>3</sup> Since significant development of the primary teeth occurs before birth, intrauterine malnutrition, or inadequate nutrient intake during early infancy may cause irreversible damage to the oral structures. Calcification of the upper central incisors begins at three to four months in utero, and the crowns are completed by four to five months of age. Development of the first molars begins at five months in utero and is completed by six months of age.<sup>5</sup> Eruption of the primary and permanent teeth may be delayed in premature infants when compared with full-term babies.

Enamel defects have been reported in a high number of pre-term infants with very-low birthweights (VLBW  $\leq$  1,500 gm).<sup>6</sup> More porous dental enamel and distinct subsurface lesions were detected in Swedish infants with birthweights less than 2,000 grams.<sup>7</sup> Generalized enamel hypoplasia results from incomplete or defective development of the enamel matrix resulting from injury to the ameloblast cells. Enamel defects may also be caused by a calcium or vitamin D deficiency, local infection, use of tetracycline, trauma, or severe asphyxia.

In VLBW infants, there is a strong correlation between surface defects such as pits and grooves in the enamel surface and risk for early childhood caries (ECC).<sup>6</sup> Cross-sectional studies of Australian aboriginal, Thai, and Chinese children have shown that enamel hypoplasia is associated with dental caries.<sup>8,9,10</sup> In a group of 25 VLBW pre-term children followed until 4.3 years of age, an average of 7.6 primary teeth had enamel defects compared with 1.0 defects in the teeth of normal birthweight children.<sup>11</sup>

Craniofacial malformations appear to have many characteristics in common with neural tube defects (NTD). Folic acid supplementation during the first months of pregnancy reduces the risk of having a child with NTD. Cleft lip, with or without cleft palate (CLP), affects about 1 in 1,000 infants.<sup>12,13</sup> There is increasing evidence that folate supplementation prior to and during early pregnancy may be beneficial in preventing orofacial clefts.<sup>14</sup> In a Hungarian case-control study, folic acid supplementation during the periconceptual period reduced the number of orofacial clefts.<sup>15</sup> A clinical trial carried out in the Czech Republic showed that a regimen of multivitamins and folic acid supplementation before conception and during pregnancy prevented facial cleft anomalies.<sup>16</sup> Women were chosen for the study who had had one occurrence of CLP among first-degree relatives. Vitamin supplementation was associated with a 65% decrease in the recurrence of cleft lip/palate among their offspring.

In the United States, a case control study involving women who had 309 cleft-affected births, a 48% risk reduction for a second CLP birth was found among mothers who used multivitamins containing folate during the periconceptual period.<sup>12</sup> For women of childbearing age, a daily intake of 400  $\mu$ g of folate is recommended. Larger doses of folate are not needed to prevent CLP. Multivitamin supplementation during the second and third trimesters does not reduce the risk of CLP. The U.S. Centers for Disease Control and Prevention has reported that only a third of women of childbearing age in the United States consume a supplement

containing the recommended amount of folic acid—400 ug during adulthood or 600 ug during pregnancy.<sup>17</sup>

Children with CLP disorders have more decayed, missing, and filled teeth than children without these conditions. Lactobacillus and yeast levels were higher but no significant differences in levels of *mutans streptococci* were observed in 96 children with a cleft condition as compared with age and sex matched healthy controls.<sup>18</sup>

### Gastroesophageal reflux

Gastroesophageal reflux (GER) is very common in children with cerebral palsy and severe mental retardation.<sup>19</sup> Erosion of primary and permanent teeth results from regurgitation of the acidic gastric contents into the mouth.<sup>20</sup> The surface enamel is eroded away by the stomach acid exposing the dentin. Children may experience sensitivity to hot and cold foods. When extensive tooth structure is lost, severe pain may result. Symptoms of GER in children include difficulty in sleeping, feeding problems, general irritability, bronchitis, laryngitis, asthma, and anemia. Restoration of a child's dentition may involve covering all the surfaces of molars with stainless steel crowns or a plastic composite resin. Medications can be prescribed to reduce GER. Systemic and topical fluorides are recommended to prevent enamel erosion.

### Dental caries

Dental caries, the most common chronic disease of childhood, occurs five to eight times more frequently than asthma, which is the second most common disease in children.<sup>21,22</sup> Caries is a source of chronic pain for many children and the cause of frequent school absenteeism. By second grade, half of all children have caries in their primary or permanent teeth.<sup>23</sup> By the time that youth finish high school, about 80% have caries. The amount of untreated decay in children is startling. Data from the third Health and Nutrition Examination Survey (NHANES III) showed that 16% of two to four year-olds, 29% of children ages six to eight years, and 20% of 15 year-olds, had untreated decay.<sup>23</sup> About 80% of the dental decay in permanent teeth is concentrated in 25% of 5 to 17 year-olds.<sup>24</sup> The prevalence of decay is greater among children from low-income and minority families. Their parents often lack education about preventive dental measures that could reduce their children's risk of dental disease. With the family's limited social and economic resources, these children are hindered from maintaining or improving their oral health.

Large oral health surveys to determine the rates of decay in children with neurodevelopmental disabilities are lacking. Caries rates are thought to be similar for

children with developmental disabilities and healthy children if they have healthy diets and good oral hygiene. Many of these children are less mobile and depend on their caregivers to provide snacks. Higher caries rates are seen in children with oromotor dysfunction, unhealthy dietary patterns, poor oral hygiene, or those who use a sucrose-based medication on a daily basis.

Dental caries is a diet-dependent bacterial infectious disease. The newly erupted primary or permanent tooth with a thin layer of immature enamel, enamel defects, or deep pits and fissures is more susceptible to decay.<sup>25</sup> *Mutans streptococci* (*S mutans*) are normal inhabitants of the human oral flora. High numbers of these acidogenic bacteria are necessary for initiation of dental caries.<sup>26</sup> But the presence of *mutans streptococci* is not enough for clinical disease to develop. *S mutans* require fermentable carbohydrate to support their metabolism.

Mono- and disaccharides such as sucrose, fructose, and glucose enable the dental plaque microbiota to multiply, colonize the tooth's surface, and form sticky dental plaque (Table 3). Organic acids, the byproducts of bacterial metabolism of carbohydrates, demineralize tooth enamel, thus increasing the risk of dental decay. The critical dental plaque pH is 5.5 to 5.7; below this level, demineralization of the tooth occurs.<sup>27</sup> The sources of sugars in processed foods most frequently consumed by children 2 to 11 years of age are fruitades/drinks, milk products, breakfast cereals, cookies and cakes, regular soft drinks, and candies, the latter two being the top sources of added sugars in children's diets.<sup>28</sup> A high intake of added sweeteners displaces more nutrient-dense foods and provides excess calories as well as increasing the cariogenicity of the diet. Added sugars represent 16% and 19% of the total calorie intake of 2 to 5 and 6 to 11 year-olds, respectively.<sup>28</sup>

The role of diet is complex and extends beyond the quantity of sugary foods eaten (Table 4). Frequent eating extends the period of time the pH stays below the critical level. When no cariogenic food is present in the mouth, between meals and snacks, remineralization of dental enamel occurs. Only if the demineralization phase, associated with frequent snacking, exceeds the remineralization period will cavitation occur. Children with caries eat snacks more frequently than those without decay.<sup>16</sup> Feeding is often a stressful time for parents of children with special health needs. Obtaining adequate calories to support growth is a challenge in children with neurodevelopmental disabilities.<sup>1</sup> Parents may provide calorie-dense carbohydrates that are cariogenic on a daily basis. Eating six times a day may be necessary to obtain the nutrients needed for growth. Choosing foods of low cariogenicity for snacks becomes

prudent (Table 5). Instant breakfasts made with whole milk are high calorie and nutrient dense. They may be preferable at snack time to the empty calories of a cookie. Children need to brush their teeth after such a snack. Children with metabolic disorders such as phenylketonuria or galactosemia may be dependent on a synthetic diet that is high in some sugars to provide adequate calories. If the formula is consumed frequently during the day, they are at increased risk for caries. Rinsing with water should follow each feeding.

Products that are sticky and are retained in the mouth for long periods of time are more cariogenic than foods that clear the oral cavity quickly. Between-meal intakes of a cooked starch-sugar combination such as graham crackers or a muffin and the frequency with which they are eaten play a prominent role in the development of carious lesions.<sup>30</sup> Particles of crackers, cookies, breads, or pastries may become lodged between the teeth for up to two hours. This extends the period of time that acid production occurs. Autistic children usually have a normal eating pattern; however, soft sticky foods were preferred by nearly one-half of surveyed children.<sup>31</sup> Pouching food in the cheek occurs in a small number of children and increases caries risk.

There are protective foods that will counter the harmful effects of fermentable carbohydrates when eaten at the same time. Using plaque pH telemetry cheeses, meats, nuts, seeds, and vegetables have been shown to be nonacidogenic (Table 5). Intake of cheese following a sweet food lowers caries risk by increasing saliva production, and the presence of protein, calcium, and phosphorus provide buffers that neutralize acids generating the *S mutans*. Dairy foods generally have low cariogenic potential.<sup>32</sup> In one study, dairy products—cheddar cheese, skim, 2%, and whole milk, chocolate milk, and orange juice—permitted remineralization of dental enamel, whereas, apple juice, a cola beverage, and strawberry yogurt caused caries progression in the enamel and dentin.<sup>33</sup>

Milk does not present a cariogenic challenge except when used inappropriately in the nursing bottle. The cariogenicity of cow's milk has been carefully scrutinized. Rats fed milk and cheese do not develop more caries than animals given water.<sup>39</sup> When desalivated rats that are at high risk for caries are given 2% milk or reduced lactose milk, they remain free of caries. Some infant formulas are more cariogenic than others.<sup>35</sup>

### Early childhood caries

Dental caries in infants and toddlers usually occurs in the primary upper incisors, followed by the upper first molars, canines, and finally the upper second molars.<sup>36</sup> ECC, also known as nursing caries, nursing bottle caries,

and baby bottle tooth decay, occurs in 5% to 10% of children 2 to 3 years old. But a much higher prevalence of ECC (68%) has been reported in Navajo preschool children.<sup>37</sup> Twenty-five percent of Head Start children in Alaska had three or more decayed upper incisors.<sup>38</sup> The prevalence of ECC in children with special health care needs is not documented. Because the nursing bottle is often used for an extended period of time by those with developmental disabilities such as Down syndrome, ECC rates may be elevated.<sup>39,40</sup> A high level of caries in the maxillary, primary teeth increases the risk that a child will have further caries in the primary or permanent teeth.<sup>41,42</sup>

Early childhood caries is associated with inappropriate feeding of sweet liquids, formula, cow's milk, fruit juices, or fruit drinks in a bottle, especially at bedtime.<sup>36</sup> Saliva flow subsides during sleep, allowing sweet beverages to pool around the upper teeth, which in turn initiates demineralization. Giving a bottle at naptime or bedtime is more often a practice of less educated, low-income mothers, newly arrived immigrants, and ethnic or minority caregivers. Not all children who take a bottle to bed will develop nursing caries,<sup>43</sup> however. Other dietary habits in preschool children also increase caries risk. Frequent intake of sugar-containing snacks by infants and toddlers is an overlooked factor.<sup>44</sup> Crackers, teething biscuits, raisins, breakfast cereals, and cookies are often offered to infants and toddlers.

Mothers of ECC children often have high caries rates themselves and high levels of cariogenic bacteria. Infants do not harbor *S mutans* until teeth erupt in the mouth.<sup>45</sup> These bacteria cannot adhere to the soft oral tissues, but require a hard nondesquamating surface. Infants most often acquire *S mutans* from their mothers. The extent of *S mutans* colonization and the future caries experience of a child are correlated with the mother's salivary level of *S mutans*. Mothers with high oral bacteria levels tend to have children with high levels.<sup>45,46</sup> Mothers with high levels of *S mutans* are usually in need of extensive dental work. Delay in *S mutans* colonization in infancy can reduce the risk of ECC.

There is a discrete time when infants become infected with *S mutans*.<sup>47</sup> Streptococci mutans have been reported in the mouths of 10-month-old infants. In a group of children in the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), 25% of those 12 months of age or younger had detectable levels of *S mutans*, whereas in the 15-month-old group, 60% were colonized.<sup>30</sup> Transmission of bacteria from mother to child occurs when kissing on the lips and sharing feeding utensils. The earlier *S mutans* are detected in the mouth, the higher the caries rates experienced. Effort to delay infecting children has been effective in lowering

caries levels. Swedish researchers have demonstrated that nutrition counseling and use of chlorhexidine gel, an antimicrobial product that prevents plaque accumulation on the teeth, daily for two weeks by mothers with high oral bacteria levels delayed the time when children acquired *S mutans*.<sup>48</sup>

Recently, Finnish researchers examined the effect of xylitol gum chewing on reducing the salivary microbial levels of highly infected mothers and the time their infants became infected.<sup>49</sup> The sugar alcohol xylitol has been shown to inhibit *S mutans* metabolism. Daily use of xylitol chewing gum by the study group was compared with women given chlorhexidine rinse or a fluoride varnish therapy at 6, 12, and 18 months after birth of their infants. The maternal levels of *S mutans* in all three groups were similar throughout the study, but children's microbial levels differed. At 2 years of age, children whose mothers were in the xylitol group had a significant reduction in the probability that they were infected with *S mutans* (9.7% of xylitol group, 28.6% of chlorhexidine group, and 48.5% of the fluoride group). At five years of age, caries in the xylitol group was reduced about 70% when compared with the fluoride varnish and chlorhexidine groups.<sup>50</sup>

Human milk is recognized as the healthiest food for infants during the first year. In laboratory studies, breast milk alone did not damage tooth enamel. But the buffering capacity of human milk is low. When sugars are added to the diet in snacks, breast milk may not neutralize acids produced.<sup>51</sup> Nursing caries has been most often observed in breast fed infants who slept with their mothers and nursed *ad libitum* through the night. If the child sleeps with the nipple in the mouth, milk pools around the teeth. High counts of *mutans streptococci* and lactobacilli have been reported in breast fed infants with rampant caries.<sup>52</sup> In those studies, other carbohydrates found in the children's diet which may contribute to caries were not determined.

Fruit juices have become the predominant beverage for many infants and children, replacing drinking water and milk. During 2000, 55% of all WIC children in a metropolitan county of Washington State had four or more servings of fruit juice, and 38% had five or more servings of juice daily.<sup>53</sup> The shift in fluid intake from water and milk to fruit juices and flavored soft drinks by children and teens has nutritional and dental implications. When compared to milk, most fruit juices and soft drinks have a low nutrient-to-calorie ratio. Four ounces of apple juice contains three teaspoons of sugar. Colonization of *S mutans* was much higher in 6- to 24-month-old children who consumed sweetened beverages rather than milk in their bottle.<sup>44</sup> If juice is sipped over an extended time period, enamel demineralization may

occur. A high intake of juice promotes childhood obesity.<sup>54</sup> Liquid preferences in the preschool years are a factor in establishing lifetime dietary patterns leading to obesity. To support nutritional and oral health in infants, fruit juice intake should be limited to four ounces daily.<sup>45</sup>

Milk is the principal source of calcium and vitamin D for children. When juice replaces milk, mineralization of bones and teeth may suffer because calcium intake is inadequate. There is increased risk that children will not attain peak bone mass in their teens when dietary calcium is lacking. A high percentage of canned juices often used by infants and toddlers may have suboptimal levels of fluoride.<sup>55</sup> When juices rather than water are consumed by children living in fluoridated communities, protection against caries is lost.<sup>55</sup> In 60 juice samples, 58% had a fluoride content below .8 parts per million. Juice should be provided in a cup, not a bottle, at about seven months of age. Four to six ounces of juice (a small juice glass) per day between infancy and six years of age is prudent.<sup>45</sup>

Child rearing practices are also associated with nursing caries risk.<sup>56,43</sup> Sleep problems were found to be a behavioral risk factor for low-income mainly African American Seattle children with ECC.<sup>57</sup> These children slept through the night fewer times, awoke more often at night, and were more often fed on demand upon waking when compared with caries-free children. Weaning from the bottle to the cup by 12 months of age is an important ECC preventive measure. Transition to the cup occurred six months earlier in the caries-free Seattle children.

Some parents do not consider primary teeth important enough to seek treatment for their child when decay occurs. An abscessed primary tooth can damage the underlying permanent tooth bud. The functions of primary teeth are not well understood by parents. Healthy primary teeth are critical to a child's total body health, to allow clear speech, permit chewing of food, enhance facial appearance and self-esteem, and to maintain space for permanent teeth. Health care providers who provide anticipatory guidance regarding sleep problems and bottle use to parents of newborns help to prevent caries in the primary teeth (Table 6).

### Use of medications

Long-term medication use presents several challenges to a child's oral health. Cough preparations may be formulated with syrups containing high concentrations of glucose, high fructose corn syrup, fructose, or sucrose to improve palatability. These medications, if taken at naptime or bedtime, can be particularly harmful to teeth. Unless water is offered after the medication, syrups will be retained in the mouth because saliva flow subsides during sleep. When compared with their healthy

siblings, chronically ill children taking long-term liquid oral medications had significantly more decay in their anterior teeth.<sup>58</sup> There are alternative sugar-free medications that can be prescribed.<sup>59</sup>

Dry mouth is a side effect of some pediatric medications. Asthmatic children often use albuterol, a bronchodilator that depletes saliva flow, to control their condition. In a group of 125 asthmatic children, higher levels of decayed, missing, and filled primary and permanent teeth occurred in the asthmatics than their healthy peers.<sup>22</sup> Saliva is important in countering acid attacks on the tooth and protects the hard and soft tissues as well as facilitating chewing, swallowing, and speaking. The protein, bicarbonate, and phosphates found in saliva neutralizes plaque acids. The calcium, phosphorus and fluoride in saliva promote remineralization of tooth enamel. Saliva also aids in clearing food particles and acid. Pediatric drugs that cause dry mouth include antihistamines, antidepressants, antibiotics, and antiesophageal reflux agents. Dehydration is a special concern in children with special health needs because fluid intake is often low. Offering fresh water regularly is important. There are other measures that lubricate the mouth or stimulate saliva flow that may increase oral comfort and relieve dryness (Table 7).

Two nutrients used by children with disabilities that interact with medications are vitamin D and folate. Dilantin, a seizure medication, interferes with vitamin D and folate metabolism.<sup>1</sup> A vitamin D deficiency hinders the absorption of calcium and phosphorus, thereby interfering with the mineralization of bones and teeth. Folate deficiency may result in development of lesions on the lips or a sore tongue. Daily intake of a liquid vitamin supplement may not prevent folic acid deficiency. Liquid vitamin supplements often lack folic acid because this vitamin is unstable in a liquid environment.

Dietary guidelines for promoting oral health in infants and toddlers are aimed at preventing ECC and coronal decay in lower molars of newly erupted primary teeth. The costs of ECC to families and to society are enormous. Children who develop ECC are at high risk of developing new lesions in the primary and permanent teeth. Complex restorative treatment and extractions of teeth at an early age are traumatic for children and makes them fearful of future dental visits. Dental care costs often exceed \$1,000, and if the treatment is provided in the hospital under deep sedation or general anesthesia, additional costs may be \$3,000 or more.

Primary prevention of ECC must begin in the prenatal period. Bringing disadvantaged expectant mothers into the dental care system is a first step. During prenatal counseling of parents, anticipatory guidance about

transmission of bacteria from mother to child, appropriate use of fluorides and the nursing bottle, oral hygiene practices, and snacking can be provided (Table 7). To prevent early rampant decay in children with disabilities, teachers, therapists, and medical providers must include oral health education in their encounters with parents of these children. Attitudes and knowledge of the expectant parents toward preventive dental practices will influence their interest in seeking dental care for their infants. The American Academy of Pediatric Dentistry recommends that the first dental examination for a child should occur after the first tooth erupts or no later than one year of age. High-risk children generally do not receive a dental examination until disease occurs because dental providers willing to care for low-income children are lacking.

The multifactorial etiology of dental caries must be considered when designing a prevention program. Too often the message given to parents is that the child must stop sleeping with the bottle and stop eating candy. The dietary factors related to dental caries are much more complex than exposure to sucrose. The total amount of sugar eaten may not be as important as the eating pattern (frequency of intake) and the retentive nature of the food. Decreasing sugar intake, infrequent snacking, avoidance of sticky carbohydrates between meals, plaque removal, exposure to fluoride, and the use of sealants are all important in preventing further decay (Table 8). Identifying children with high caries rates in their primary teeth is critical if dental decay in the permanent teeth is to be prevented. WIC needs to incorporate an oral health component in the physical evaluation. WIC staff in Washington State have been trained to examine the anterior teeth of infants and toddlers for white spot lesions. They provide anticipatory guidance to parents and make referrals for children exhibiting signs of decay.

### **Directions for future research**

Further studies are needed to document the food choices and eating patterns that affect the oral health of children with developmental disabilities. The findings of these studies would be useful in developing nutrition education materials for clinicians and parents. Inappropriate use of the baby bottle is no longer considered the sole etiological factor for early childhood caries. Few resources have been allocated to understanding the cultural and behavioral factors that lead parents to engage in unhealthy feeding practices that lead to early childhood caries. Human clinical dietary trials to measure the cariogenicity of foods or the effects of certain eating patterns on the development of dental caries are unethical today and cannot be undertaken. This does not preclude the use of already developed

intra-oral remineralization-demineralization models and in vitro tests to measure snack food cariogenicity. Food manufacturers should be encouraged to develop more snack foods prepared with noncariogenic sweeteners such as aspartame, xylitol, and sucralose.

The research agenda established at the Conference on Early Childhood Caries in 1997 remains to be implemented.<sup>61</sup> The following nutrition related issues require further investigation.

- Conduct an oral health survey of children with developmental disabilities to determine the prevalence of dental caries associated with neurodevelopmental disabilities, craniofacial malformations, metabolic disorders, and premature birth.
- Document the feeding practices of caretakers of children with disabilities.
- Establish the relationship between unhealthy early feeding practices and the subsequent harmful snacking patterns.
- Determine the behaviors associated with prolonged breastfeeding that cause ECC.
- Identify behavioral factors that may be linked to the development of ECC.
- Establish the effectiveness of oral examinations by WIC personnel in preventing early dental caries.

- Establish the role of cariogenic snacks in the prevalence of ECC in children.
- Conduct prospective studies of behavioral interventions that can be used by stressed families to eliminate unhealthy infant feeding practices.
- Test self-efficacy training and behavior modification techniques that would enable parents to provide a diet promoting oral health.

**Table 1—Feeding problems of special health needs children that have dental implications**

Prolonged use of nursing bottle
Low fluid intake
Gastroesophageal reflux
Gagging, vomiting, rumination
Oral hypersensitivity
Low calorie intake
Extended eating time
Disruptive behavior at mealtime
Refusal to consume specific foods or groups of foods

**Table 2—Effects of nutrient deficiencies on tooth development<sup>4</sup>**

<b>Nutrient</b>	<b>Effect on Tissue</b>	<b>Effect on Caries</b>	<b>Human Data</b>
Protein/calorie malnutrition	Tooth eruption delayed Tooth size Enamel solubility decreased Salivary gland dysfunction	Yes	Yes
Vitamin A	Epithelial tissue development Tooth morphogenesis dysfunction Odontoblast differentiation Enamel hypoplasia	Yes	Yes
Vitamin D/ calcium/ phosphorus	Lowered plasma calcium Hypomineralization (hypoplastic defects) Tooth integrity compromised Delayed eruption patterns	Yes	Yes
Ascorbic acid	Dental pulpal alterations Odontoblastic degeneration Aberrant dentin	No	No
Fluoride	Stability of enamel crystal (enamel formation) Inhibits demineralization Stimulates remineralization Mottled enamel (excess) Inhibits bacterial growth	Yes	Yes
Iodine	Delayed tooth eruption Altered growth patterns Malocclusion?	No	Yes
Iron	Slow growth Tooth integrity? Salivary gland dysfunction	Yes	No

**Table 3—Cariogenic carbohydrates**

Carbohydrate	Food Source
Glucose, dextrose, sucrose	Candies, fruit drinks, granola bars
Fructose	Fruits, fruit juice, honey
High fructose corn syrup	Soft drinks
Sucrose, brown or powdered sugar, molasses	Fruits, vegetables, fruit drinks, frozen desserts, muffins, cookies, cakes
Cooked starch	Baked goods, snack chips, crackers, breads

**Table 4—Eating patterns that contribute dental caries**

Eating Pattern	Examples
Frequent snacking 2 or more times between meals	M & M's Sipping juices or soft drinks Soda or graham crackers Pretzels, ready-to-eat breakfast cereals
Sticky, retentive snacks or slow dissolving carbohydrates	Raisins, other dried fruits Fruit roll Bananas Caramels, jellybeans Peanut butter and jelly sandwich
Sequence of eating foods and time of day	Chewable vitamins given at end of meal Snack cookie before naptime Ice cream at bedtime

**Table 5—Cariogenic potential of foods and snacks<sup>29</sup>**

Noncariogenic	Low Cariogenicity	High Cariogenicity
Nuts*	Chocolate milk	Cookies
Sunflower & pumpkin seeds	Fresh fruits	Cake
Popcorn*	Whole grain products	Candy
Tuna fish		Raisins and other dried fruits
Chicken, eggs		Fruit Rolls
Cottage cheese		Breakfast bars
Cheese cubes		Doughnuts
Vegetables <sup>o</sup>		Soda crackers
Seltzer water		Pretzels
Diet soft drinks		Sweetened dry cereals
Plain yogurt		Granola bars

\*Do not give to children under three or those who have swallowing disorders.

<sup>o</sup>Lightly steamed vegetables are safer for young children.

**Table 6—Guidelines for promoting oral health among infants**

- Hold infant for bottle and breast feedings.
- Do not permit a child to nap or sleep with a bottle containing milk or fruit juice.
- Offer only water in a bottle given at naptime or nighttime.
- Eliminate pacifiers dipped in honey or another sweetener.
- Wean the child from the bottle by one year of age.
- Provide no more than 4 ounces of fruit juices in a cup instead of a bottle daily.
- Avoid allowing a child to sip juice continuously from a cup during the day.
- Choose fresh fruits, lightly cooked vegetables, or whole-grain foods for snacks.
- Wipe the teeth and gums with a soft cloth after feeding.
- Use appropriate systemic and topical fluoride supplements.

**Table 7—Oral health guidance for children with drug-induced xerostomia**

- Brush and floss teeth after meals or snacks.
- Use a fluoride rinse daily.
- Drink water hourly.
- Use sugarless gum daily.
- Have teeth professionally examined and cleaned 3-4 times/year starting at 1 year of age.

**Table 8—Guidelines for decreasing the cariogenicity of the diet for preschool children with developmental disabilities<sup>60</sup>**

	<b>Level of Evidence</b>
1. Use concentrated sources of sugars sparingly.	I
2. Limit between-meal snacking to three times over the day.	II
3. Eliminate evening snacks.	III
4. Choose noncariogenic foods for snacks.	III
5. Offer a noncariogenic food such as cheese with cariogenic foods such as crackers or cookies.	III
6. Avoid offering slow-dissolving sugar-containing foods, such as lollipops.	I
7. Offer cariogenic sticky, retentive foods at mealtime.	I
8. Rinse the mouth with water following juice or snack intake.	III
<b>Level</b>	<b>Evidence</b>
I	Evidence from at least one randomized controlled trial.
II	Evidence from at least one nonrandomized controlled trial, cohort or case-control study.
III	Evidence from case reports, epidemiologic studies, clinical experience, or reports of expert panels.

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# Oral-motor Dysfunction

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Oral health is a broad topic. Although traditionally focused on *dental* health, oral-motor control is central to the functional well-being of the mouth. The prototype for oral-motor dysfunction and its potentially devastating consequences is the child with cerebral palsy who has substantial oral-motor involvement. The purpose of this article is to outline the spectrum of oral-motor dysfunctions, focusing mainly on cerebral palsy as the underlying disorder.

## Structure and function

Effective oral functioning—chewing, swallowing, speaking, etc.—is dependent upon the structural integrity of oral structures and on the functional integrity of neural mechanisms serving the face, mouth, pharynx, and to a lesser extent, respiratory control. As outlined in Table 1, varying degrees of oral dysfunction will ensue as a consequence of:

1. Loss of extra-oral architecture; for example, radical lip or buccal surgery for cancer or trauma, fractures or tumors of the mandibular or maxillary bones, etc.
2. Intra-oral structural problems with the teeth, tongue, palate; for example, congenital clefts, loss of teeth, etc.
3. Central nervous system (CNS) motor encephalopathies, either progressive or static; for example, the numerous degenerative CNS disorders and cerebral palsy.
4. Peripheral neuromuscular system disorders; for example Bell's palsy, myasthenia gravis, muscular dystrophies, etc.
5. Joint or soft tissue restrictive diseases; for example, rheumatoid arthritis, temporomandibular joint problems, arthrogyposis, etc.
6. Severe intellectual limitations or psychoemotional disorders; for example, severe to profound mental retardation, dementia, factitious symptoms, etc.

The oral-motor consequences of these disorders can be viewed as a continuum of oral performance impairments (Table 2), which include speech problems (articulation and phonation), feeding and swallowing difficulty, drooling, upper respiratory congestion, and pulmonary aspiration. They often but not always go hand-in-hand. For example, severe drooling without associated speech impairment is virtually unheard of. Conversely, drooling associated with normal or near-normal speech will almost always be mild and carries a good prognosis for resolution with minimal treatment. Fairly extensive literature is available on each of these impairments, addressing issues of epidemiology, diagnosis, and

management. I have chosen one topic, drooling, to present in limited detail in order to demonstrate the breadth of literature in existence and the complexities involved in each individual problem.

## Drooling and its treatment

Saliva serves a number of very important functions. It aids in protecting the teeth from decay and the gingival tissues from inflammation and periodontal disease. It keeps the oral mucosa comfortably moist and acts as a lubricant for promoting swallowing and as a solvent for facilitating taste. It provides cleansing and antibacterial actions in the mouth, cutting down on breath odor. Lastly, it promotes protein and carbohydrate breakdown through salivary amylase, pH modulation, and other factors.<sup>1,2</sup>

Although good prevalence data are unavailable, it is estimated that 10% of children with cerebral palsy have drooling problems significant enough to interfere with daily social and practical functions.<sup>3,4</sup> An unknown number of retarded individuals are further handicapped by their drooling. A much smaller population of individuals exists who have lost the structural integrity of the jaw and/or lips as a result of trauma or oropharyngeal tumors with resultant chronic drooling.

The term sialorrhea implies excessive secretion of saliva, although most assert that saliva is not over-produced in children who drool but that inadequate swallowing and lip closure are the critical factors.<sup>2,4,5,6</sup> The standard concept of drooling refers to visible, anterior (labial) spill of saliva. Individuals with oral-motor dysfunction also have oral retention in sublingual and buccal pools and pharyngeal retention. The pooling of saliva, at times mixed with food, may be the mechanism of malodor. The term “posterior drooling” has been applied to the situation in which oral secretions are not lost externally but pool in the hypopharynx where they should normally stimulate a swallow reflex.<sup>7</sup> In the absence of adequate swallowing, they produce a clinically more serious posterior spill through the faucial isthmus into the pharynx, which results in congested breathing, coughing, gagging, vomiting, and at times aspiration into the trachea. Although severe oral-motor dysfunction is a factor in posterior drooling, there is likely a significant pharyngeal sensory deficit and/or a central disruption of the sensorimotor connections, interfering with reflex swallowing. The physiology of where and how the swallowing mechanism fails has received minimal study.<sup>8</sup> Disturbances in oral sensation and insufficient sensory appreciation of external salivary loss contribute to drooling in children with mental retardation and cerebral palsy.<sup>9,10</sup>

Many modalities—various hands-on therapies, medications to dry secretions, surgery to eliminate gland function, oral appliances to stimulate swallow, even radiation—have been proposed, often in combination, to treat drooling (Table 3). No one option is universally successful, and many treatments have potential complications. Each of these treatment approaches has been quite extensively studied in its own right, but the quality of the science is modest—virtually all descriptive case series or individual case reports. Only a small, representative sampling of the articles available will be cited in this overview.

Since positional and oral control problems predispose to drooling, it follows that treatments to improve body position and posture along with specific oral-motor therapy have an important place in the management of drooling. Occupational, physical, and speech/language therapists employ handling techniques and the use of assistive equipment to enhance head control, stabilize body position, and normalize muscle tone in an effort to accomplish this.<sup>11,12</sup> Oral stimulation techniques emphasize the enhancement of sensorimotor feedback mechanisms.<sup>13,14</sup> In general there is a paucity of high level clinical research to document the effectiveness of hands-on therapy in the area of oral-motor dysfunction and, specifically, drooling control.<sup>15</sup>

Behavior modification programs to promote awareness of salivary escape and to encourage regular swallowing have been advocated.<sup>16</sup> Rapp, for example, successfully trained a group of children with cerebral palsy and mental retardation to swallow more frequently.<sup>17</sup> A portable device that delivered an auditory cue at regular intervals was added as a prompt for use in school. As with the therapy studies, most of the published behavior modification studies suffer from the problem of small sample size, and all are Level III evidence at best (cf: the rules of evidence, U.S. Preventive Services Task Force 1984, Sackett 1989, and Sackett *et al.* 1997).<sup>18,19,20</sup>

Little can be said about the potential advantage of oral appliances combined with therapy.<sup>21,22</sup> This approach has been slow to gain acceptance but it may have great potential. The putative effect of the appliance is to permit oral retraining by promoting jaw stabilization, lip closure, and tongue mobility. As a result, improved chewing and swallowing ensue, thereby improving feeding and diminishing drooling.

Surgeons point out that nasopharyngeal obstruction causes mouth-open posture, which is a strong promoter of drooling. They cite several “cures” following tonsillectomy and adenoidectomy.<sup>23,24,25</sup> However, for most droolers, surgery does not address the problem of inadequate swallowing so directly, and the results are

less dramatic. Ablation of one or more salivary glands decreases the quantity of saliva and alters its viscosity. Removing all salivary flow is undesirable because of the adverse effects of xerostomia on oral and pharyngeal comfort, on dental health, and on the ability to masticate and swallow food. Most plastic and oral surgeons favor procedures on the salivary glands or their ducts. Methods include extirpation of the parotid and/or submaxillary (submandibular and sublingual) glands, ligating or relocating the parotid ducts, and relocating the submandibular ducts.<sup>26,27,28,29,30,31</sup> Otolaryngologists generally favor interrupting the parasympathetic nerve supply to the salivary glands.<sup>32,33,34</sup> This accomplishes in a highly selective fashion what pharmacologic therapy can only do in a much more diffuse way. Burton has thoroughly reviewed the history of these many surgical procedures, concluding that “each of the procedures... has its devotees and detractors,” something of an understatement.<sup>35</sup> Because of each surgeon’s enthusiasm, the surgical literature, which is fairly extensive, is difficult to evaluate. As seen in other treatment studies, measurement techniques, outcome measures, and long-term follow-up are weaknesses of most of these surgical reports. Essentially all are case series qualifying for Level III in the rules of evidence as outlined in the U.S. Preventive Services Task Force guide, equivalent to Sackett’s Level V.<sup>19,36</sup>

Radiation to the parotid and submandibular glands was formerly advocated as a method to suppress salivary secretion, but has been criticized because of the long-term hazards of radiation injury in terms of growth arrest and neoplasia. Even small doses of radiation in children are known to produce skin and thyroid cancers, leukemia, and growth arrest with facial asymmetry.<sup>37,38</sup>

Radiation therapy has been appropriately abandoned in pediatric populations. Experienced clinicians know that drooling surgery works well most of the time. Sialorrhea not uncommonly returns gradually over time but rarely to the degree present before surgery. Major complications, including xerostomia, are very rare but minor ones are common. Everyone is wary, of course, because of the irreversibility of the surgical procedure and the rare instance of creating a situation that is irreversibly worse.<sup>39</sup> Hence the use of medication has great appeal, and clinicians argue a trial should *always* be attempted before surgical treatment.<sup>40</sup>

Salivation is mediated through the autonomic nervous system primarily by way of the cholinergic system’s muscarinic receptor sites. Blockade of these receptors inhibits nervous stimulation to the salivary glands. With most pharmacologic treatments there is little selectivity in terms of blocking transmission at only the desired site. Anticholinergic drugs used to decrease drooling

have widespread effects manifested at all end organs that are governed by muscarinic stimulation. Although there exists a general pessimism about pharmacologic management, a modest number of drug studies accomplished in the past decade suggest somewhat greater optimism. These studies provide very good information for management purposes and demonstrate that medication is helpful most of the time — about 80% of children will achieve useful benefit.<sup>41,42,43,44,45,46,47</sup> Drug therapy is very rarely curative. None of these investigations have considered the dental effects of drooling or dental consequences of its treatment.

### What does this all have to do with the teeth?

Oral/dental health problems can cause problems in tissues in proximity to or connected to the mouth by direct extension (for example, respiratory tract infection or obstruction) and can also be the source of systemic difficulties (for example, endocarditis). In children with cerebral palsy, dental health is negatively affected indirectly by virtue of the many associated deficits, for example seizures. By virtue of trauma, either self-inflicted (biting) or the consequence of a fall, the lips, tongue, buccal mucosa, or teeth can be badly damaged during a motor seizure. Gingival hyperplasia associated with anticonvulsant drugs makes the gingivae unsightly and prone to inflammation while the teeth become more difficult to clean and therefore more prone to caries. The mouth is connected to the rest of the gastrointestinal tract, and more distant gastrointestinal problems can influence teeth (for example, gastroesophageal reflux). Children with central nervous system disorders, especially severe CP and mental retardation, are at markedly higher risk to have gastroesophageal reflux than the general pediatric population.<sup>48</sup> Reflux of the acidic contents of the stomach into the mouth causes dental erosions, a complication of reflux essentially never addressed in pediatric literature.<sup>49,50,51</sup> In contrast, reflux gaining access to the respiratory tract and producing reactive airway symptoms or aspiration pneumonia is well-documented in pediatric textbooks. Unfortunately, a nicely done study to assess the effect of anti-reflux medication on drooling failed to address dental issues.<sup>52</sup>

Because of abnormal orofacial muscle tone and postural abnormalities, children with CP are more prone to malocclusion and gingivitis.<sup>53,54,55</sup> Temporomandibular joint contracture has been reported once but probably is under-recognized.<sup>56</sup> Developmental enamel defects are prevalent in the CP population and are perinatal or prenatal in origin, probably sharing the same etiologic insult as the brain.<sup>57</sup> Of great interest is the finding of Pope and Curzon that the dental caries experience of children with CP was *the same* as normal controls, but

more extractions, fewer restorations, and poorer quality restorations typified the CP group.<sup>53</sup>

Surgical treatment, because of its potential to irreversibly produce complete loss of saliva, has received some limited scrutiny in terms of dental outcomes. Several studies have shown an increased caries risk (in the absence of xerostomia) for children with CP following surgery to control drooling.<sup>58,59,60</sup>

### Conclusion

Oral-motor function is considered an integral aspect of oral health. Oral-motor dysfunction can result in a spectrum of oral health problems, some but not all affecting the teeth. Although there is considerable literature available on some of these issues, the great majority of the scientific evidence that has been generated is low on the rules of evidence scale. There remains enormous room for high quality research in every topical area touched on in this overview.

**Table 1—Causes of oral-motor dysfunction**

Structural damage or deformity
<ul style="list-style-type: none"> <li>• extra-oral</li> <li>• intra-oral</li> </ul>
CNS encephalopathies
<ul style="list-style-type: none"> <li>• static</li> <li>• progressive</li> </ul>
Peripheral neuromuscular disorders
<ul style="list-style-type: none"> <li>• cranial nerves</li> <li>• neuromuscular junction</li> <li>• muscle</li> </ul>
Joint and soft tissue disease
Disturbances of higher cortical function

**Table 2—Spectrum of oral-motor impairment**

Speech: poor articulation
Feeding dysfunction:
<ul style="list-style-type: none"> <li>• suck</li> <li>• chew</li> <li>• tongue mobility</li> </ul>
Swallowing dysfunction:
<ul style="list-style-type: none"> <li>• drooling</li> <li>• aspiration</li> <li>• oral-sensory deficit</li> </ul>

**Table 3—Treatments for drooling**

Positioning and seating
Oral-motor/sensory therapy
Behavior management/modification
Intra-oral appliance
Pharmacotherapy
Surgery
(Radiation)

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# Oral Health and Speech

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## Introduction

The Executive Summary of the 2000 Surgeon General's Report on Oral Health states that "oral health means much more than healthy teeth. It means being free of chronic oral-facial pain conditions, oral and pharyngeal (throat) cancers, oral soft tissue lesions, birth defects such as cleft lip and palate, and scores of other diseases and disorders that affect the oral, dental, and craniofacial tissues, collectively known as the craniofacial complex... These are tissues that allow us to speak and smile; sigh and kiss; smell, taste, touch, chew, and swallow..."<sup>1</sup> An outgrowth of this report was the *Surgeon General's Conference on Children and Oral Health: The Face of a Child*, held in June of 2000 in Washington, D.C. One of the key themes to emerge from this conference was that special initiatives are needed to address oral health disparities in children with craniofacial conditions and other complex health conditions.<sup>2</sup>

Cleft lip and palate is the most representative and well-recognized anomaly within the spectrum of craniofacial conditions. Orofacial clefting is one of the most common of all major birth defects, with an incidence of 1/700 to 1/1,000 live births. By the above definition of oral health, the baby born with a craniofacial condition such as cleft palate with or without cleft lip presents with aberrant oral health, which immediately affects feeding, middle ear status and hearing, oral sensory and motor experiences, facial esthetics, and speech development. Moreover, there is the potential for life-long oral health disability, with secondary impact on quality of life at all levels, depending on access to care, quality and appropriateness of care, and outcome of care.

## Speech problems in cleft lip and palate

The speech impairment in cleft lip and palate is the direct consequence of the structural disorder and rearrangements caused by the cleft. Clefts of the primary palate (cleft lip alone or cleft lip and alveolus) contribute labial mobility problems that appear more cosmetic than functional, and dental and occlusal deviations that can cause speech sound distortions (such as dentalizing sounds that normally are not dentalized). They typically do not impair speech intelligibility and usually are corrected through orthodontic management and/or orthognathic surgery.<sup>3,4,5</sup> While both cleft lip and cleft palate pose obstacles to normal speech, it is the cleft palate—and associated velopharyngeal closure inadequacy—that places the child with a cleft at risk for serious speech sound learning, speech production, and speech intelligibility problems. Complicating factors of velopharyngeal closure such as post-operative oronasal fistulae,<sup>6,7,8,9</sup> palatine tonsils that may be obstructive to VP closure,<sup>10,11</sup> and adenoid tissue that may be either

beneficial or detrimental to VP closure may arise during the early school age years and can persist into adolescence. The collective and interactive impact of all of these structural bases for speech impairment as well as the interim outcomes of their physical management (surgical, orthodontic and orthognathic, prosthodontic or any combination) must get factored into ongoing speech assessment findings and recommendations for treatment, into speech remediation goals and limitations, and ultimately, into how we evaluate speech outcomes in this population.

It is well documented and common knowledge among speech-language pathologists and members of interdisciplinary teams that certain speech sound errors are commonly observed in individuals with palatal clefts. Four qualities in particular make cleft palate speech perceptually deviant and phonologically distinctive.<sup>8</sup> These are hypernasal resonance or hypernasality, which is heard primarily during production of vowels; (b) nasal air emission, nasal turbulence, both heard during production of consonants that require high oral pressures and oral release of airflow (for example, "p,b,t,d,k,g,f,v,s" etc.); (c) weakly produced consonants that occur secondary to the diminished oral pressures; and (d) so-called compensatory misarticulations that are made using atypical gestures of larynx, pharynx, and tongue. These appear to be learned early in speech development in an attempt to compensate for the faulty velopharyngeal closure mechanism. Not all cleft children use compensatory misarticulations, but in those who do, these deviant speech productions persist, even after physical management has provided physiologically adequate closure.<sup>6,9</sup>

## Craniofacial speech evaluation: a brief overview

The comprehensive craniofacial speech evaluation includes three components: the orofacial examination, the clinical speech evaluation, and instrumental assessment, and instrumental assessment of velopharyngeal function. The latter most typically involves direct imaging of velopharyngeal anatomy and physiology via videonasendoscopy, videofluoroscopy, or both. On average, the earliest age at which instrumental assessment can be accomplished is 3 1/2 to 4 years. Prior to that, treatment decisions are based solely on orofacial findings and perceptually-based judgments of speech, and specifically judgments of hypernasality, nasal air emission, and articulation, including compensatory misarticulations. Orofacial and perceptual speech findings are used to determine the need for instrumental assessment and questions to be answered by that assessment. They also prescribe the need for physical management of any malocclusion underlying speech

deviations and for fistula closure or obturation. Combined orofacial, perceptual speech and instrumental data are used to determine the efficacy and type of any physical management and the outcome of that management.

### **The orofacial exam**

While the clinical speech evaluation and interpretation of instrumental assessment data are within the purview of the craniofacial speech pathologist, the orofacial exam is interdisciplinary and has transdisciplinary significance. Although the focus may vary depending on the discipline, all medical and dental specialists involved in craniofacial health care do, or should do, an oral examination. The orofacial exam in craniofacial speech pathology is a focused exam that evaluates for structural deviations and their relationship to impaired speech production. Table 1 at the end of this paper outlines this exam and what to look for. The table is fairly self-explanatory. Different dental and occlusal problems will have differing impacts on speech.<sup>12,13,14</sup> Fistulas are hazardous to speech because air escape through a fistula can cause nasal emission of that airflow that will then distort the target consonant sound(s). And the sounds distorted relate to both location and size of the fistula.<sup>6,7,8</sup> Children who present with hypernasal speech in the absence of any history of cleft palate frequently are found to have a submucous cleft palate, based on physical findings from the orofacial exam. Problems with velopharyngeal closure, per se, and the role of tonsils and adenoid tissue in velopharyngeal closure all require instrumental assessment for definitive diagnosis.

In most cleft palate and craniofacial team settings, multi-specialty and interdisciplinary input and consensus in findings are easily obtained. But care is fragmented, or where school-based referrals are made by professionals unfamiliar with team care, non-team pediatricians and ear, nose, and throat physicians, in particular, may be the first professionals to see youngsters with suspected craniofacial speech disorders such as submucous cleft palate. Pediatric dentists are also likely to see “undiagnosed” craniofacial patients in their practices periodically. In such instances, transdisciplinary knowledge and skills<sup>16</sup> are essential if children are to receive appropriate referrals and services. This relates directly to training issues. There is some evidence to suggest that both medical and dental students lack exposure to and knowledge about cleft palate. Vallino et al.<sup>17,18</sup> conducted survey research on this topic. The dental students were from one institution and the medical students from three separate institutions. Results of the surveys revealed that while most of the 108 dental students surveyed had had some coursework on cleft palate, 45% had done no reading on the topic, roughly 88% had no clinical

experience with clefting and about a third had never seen a cleft palate. For the medical students surveyed, more than 60% said they had studied cleft palate in their coursework, and nearly 30% had done reading on the topic; 65% had seen an individual with cleft palate, and slightly less than 6% had had any clinical experience with clefting. Both groups had poor understanding of the composition of cleft and craniofacial teams. This latter finding is not surprising since the literature on health care teams suggests that there is little agreement on what comprises a health care team, how it is organized, and what its goals and objectives should be.<sup>19</sup> This type of survey could be expanded to include other dental and medical schools across the country and to look at differences among programs, particularly in relation to schools affiliated and not affiliated with a cleft palate or craniofacial center.

### **Craniofacial outcomes**

The current effort in craniofacial care is directed at preventing poor outcomes and maximizing individuals' quality of life through coordinated multidisciplinary team care and the adoption of recommended standards for that care.<sup>20,21,22</sup> Accomplishment of this effort will indeed require a number of special initiatives for both training and research. The ongoing work of the Chapel Hill-based Craniofacial Outcomes Registry<sup>22</sup> is a significant initiative in this effort. Currently, 40 U.S. teams are participating in the Registry, and 6,417 patients are registered. The rate of enrollment suggests that the total number of patients will exceed 10,000 by the end of 2001. Outcome reports on initial palate repair and on access barriers are currently in process.

### **Training initiatives**

Based on review of recent literature, clinical experience and current U.S. health care policy initiatives, six training agenda initiatives are recommended.

- Training Initiative 1: Dental and medical specialists should be better informed about speech development, disorders, and treatment, in general, and craniofacial and related developmental speech disorders in particular. This includes exposure to craniofacial team care and specialists. To this end, a course of study on speech pathology should be a part of the curriculum in all dental and medical schools. This coursework should be taught by doctoral level speech-language pathologists and should include both didactic instruction and observational experience.
- Training Initiative 2: Speech-language pathologists should be better informed about oral health, nutrition, and pediatric medicine, especially developmental pediatrics. Coursework on these

topics should be a part of the graduate curriculum in communication sciences and disorders. This coursework should be taught by the appropriate specialists.

- Training Initiative 3: Dental, medical and speech-language pathology students should be better informed about federal health care legislation and associated health care policy. A module on health care legislation, policy, and funding should be incorporated into the curriculum of dental, medical, and communication sciences and disorders training programs.
- Training Initiative 4: Interdisciplinary and related health care policy coursework for dental, medical, and speech-language pathology students could be delivered through traditional onsite scheduled lectures and observational experiences, via online distance education with asynchronous scheduling, or a combination of both.
- Training Initiative 5: Professional specialty organizations should include interdisciplinary presentations at national and regional meetings. Health care professionals should pursue continuing education outside of their specialty areas. In this regard, the American Cleft Palate-Craniofacial Association (ACPA) is an excellent forum for interdisciplinary exchange and networking within the broad spectrum of craniofacial conditions.
- Training Initiative 6: Training grants should be developed to promote transdisciplinary knowledge and skills. For example, speech-language pathologists (SLPs) could be trained to oral health screenings as a part of the routine orofacial examination. The majority of SLPs are employed in the public schools. This role expansion of the SLP could facilitate better access to oral health care, and it is compatible with Objective 21-13 of Healthy People 2000, to “increase the proportion of school-based centers with an oral health component.” This could be a joint effort of dentistry and speech-language pathology.

### Research initiatives: team care

Federal law is a major driving force for the formation and survival of teams and for collaboration in certain areas of health care. New directions toward team approaches in special education and rehabilitative services have been mandated by several federal laws.<sup>16</sup> Their implementation, however, continues to be hampered by policy issues and funding. Review of the current literature, clinical practice, and cleft and craniofacial team regimens all reveal an absence of research-based evidence that what we do works and that it works better than fragmented care. Unfortunately,

there are no data available on the outcomes of craniofacial team care or on the costs of such team care. In fact the only figure available, and often cited on the cost of craniofacial patient care, is based on 1992 dollars and estimates the cost per case at \$101,000 for a patient with bilateral cleft lip and palate.<sup>23</sup> In a 1999 state-of-the-art paper on the organization and delivery of craniofacial health care, Strauss emphasized that the health outcomes of craniofacial team management have not as yet been established in the research literature, although clinicians and administrators report many advantages of team-based care over fragmented, community-based, multi-specialty care. He commented further that as the U.S. health system changes, increasing attention will be paid to the rationale and value of cleft and craniofacial teams. And he noted that health planners are likely to ask questions such as:

- How can cleft/craniofacial teams be most effective?
- Are limitations on numbers of cleft/craniofacial teams in a region effective in controlling cost and improving quality of care? Does it result in improved outcomes for patients?
- Is team care more cost effective than fragmented care?
- What constitutes a minimal team and what constitutes an excellent team?

Answers to such questions will define the future for the cleft and craniofacial team. The desired overall outcomes of cleft and craniofacial care involve speech, esthetics, and quality of life. Individuals with craniofacial conditions should be able to speak well, look good, and feel good about their lives. To this end,

- Research Initiative 1 has as its objective to provide basic outcome data on team care for (non-syndromic) cleft palate with or without cleft lip. To accomplish this, we need to develop multi-center research protocols to study:
  - \* surgical outcomes of palate surgery as measured by velopharyngeal speech
  - \* function
  - \* surgical outcomes of facial esthetics
  - \* orthodontic/orthognathic outcomes as measured by speech articulation
  - \* quality of life outcomes
- Research Initiative 2 has the objective of obtaining basic data on cost of team-based craniofacial care. This could be accomplished by conducting a study on the economics of cleft and craniofacial team care, in partnership with major insurance providers.

## Research initiatives: speech

Advances in surgical management—earlier surgical closure of the cleft palate and improved technique, in combination with early speech intervention—appear to have helped to reduce the number of cleft palate children who have severe articulation and resonance disorders. Bzoch<sup>24</sup> looked retrospectively over the past 40 years at cleft children in his population who had demonstrated speech disorders. He reported that while 75% of 1,000 children studied in the 1960s had “cleft plate speech disorders,” only 20% of 50 children studied in the 1970s to 1980s evidenced such disorders. While this is impressive, it is data from one center and there are no other corroborating data. Blakely and Brockman<sup>25</sup> reported the results of a four-year longitudinal demonstration project with youngsters with cleft palate with or without cleft lip, where the goal was to achieve normal speech articulation, oral-nasal resonance balance, and normal hearing in 90% of the children by age five. Forty-one children and their parents participated in the study. Temporary speech appliances were provided for eight of the children to provide structurally adequate mechanisms for the duration of the project. The project was interdisciplinary, involving speech pathology, audiology, otolaryngology, pediatric dentistry and prosthodontics, and parents. The outcome was that at age five, 93% of the children had normal oral-nasal resonance and met the developmental criteria for normal articulation; 98% had normal hearing in at least one ear. Such outcomes, in larger numbers, could positively affect funding for early speech intervention and demonstrate that dollars spent on early intervention are dollars saved in later years in terms of costs to society. Kuehn and Moller,<sup>25</sup> in their 2000 state-of-the-art paper on speech and language issues in the cleft palate population, arrived at the following conclusion: “Early and aggressive management for speech and language disorders should be conducted. For most individuals born with cleft conditions, a realistic goal should be normal speech and language usage by the time the child reaches the school age years.” There is a need for multi-center studies that look at the speech outcomes of early intervention. To meet this need,

- Research Initiative 3 aims to obtain speech data on the effects of early intervention. To accomplish this, we need to conduct prospective, longitudinal multi-center studies on (interim) speech outcome.

Children with cleft lip and palate require surgical and dental management to provide a mechanism that is structurally adequate for speech. For some children, physical management alone is sufficient and speech develops normally. For other children, speech is disordered. Speech outcome in cleft palate speakers is a

primary focus of cleft care but a secondary outcome. That is, it is largely determined by the outcome of physical management. A large percentage of children with cleft palate require speech intervention. As summarized by Peterson-Falzone et al.,<sup>12</sup> estimates vary across reports, but on average about 50% require speech therapy at some point in their lives. This estimate comes from a collection of reports.<sup>24,25,27,28,29,30,31</sup> Bzoch estimated that as many as 25% to 30% of cleft palate children under team care continue to have speech problems throughout their preschool years. The published literature on speech outcomes is sparse. For the most part, the studies have been retrospective and cross-sectional in design.<sup>14,15,32,33</sup> The recent report out of the United Kingdom by Sell et al.,<sup>31</sup> is an exception; the authors used a prospective cross-sectional design. Looking at these studies collectively, the variability in age at outcome assessment, differing assessment procedures used, amounts of team care and speech therapy, and the lack of consensus on what constitutes “good” or “acceptable” speech all preclude meaningful cross-study comparisons and raise questions as to validity of findings. All of the authors commented that outcomes were disappointing. The status of outcomes research points to the need for a uniform approach to the assessment of craniofacial speech outcomes with respect to when, how, and what to evaluate. Data from the Craniofacial Outcomes Registry<sup>22</sup> and from the ACPA data base should be useful in this regard. There is a need for carefully designed, multi-center prospective longitudinal speech outcome studies in cleft lip and palate.

- Research Initiative 4 would establish a uniform approach to the assessment of craniofacial speech outcomes. This initiative involves three sequential tasks. The first is to conduct survey research to collect data on current assessment practices. The second is to use the survey results to develop a recommended protocol. And the third is to convene a group of craniofacial speech pathologists to establish consensus on a “standard” protocol.

Because we are ultimately interested in positive final outcomes and how to achieve these, two measurement endpoints are recommended for multi-center research: (1) an interim end point at age five that would evaluate the effects of early intervention; and (2) a final end point at the completion of all physical management. These end points are compatible with the mandates for early intervention and with the speech activities that comprise the developmental progression of cleft care from birth to early adulthood. (See Table 2 at the end of this paper).

Research on outcomes of speech therapy is a separate area of inquiry. Speech pathologists who deliver speech

therapy to cleft palate patients have developed many special behavioral techniques for remediation of cleft palate speech errors. But there is no scientific evidence to show that speech therapy is effective, which procedures work best, for whom, and under what conditions. Many of these have been in existence and passed along for most of the last century. And, on a clinician-by-clinician basis, these are shared, discussed, and still surviving because they work.

- Research Initiative 5 has as its objective to obtain data on the effects of traditional articulation therapy on the correction of compensatory misarticulations. This initiative would conduct multiple controlled small group studies using speech-language pathologists experienced in craniofacial speech disorders

More recently, certain instrumental approaches to assessment and treatment have been introduced. Most employ some type of biofeedback. Sporadic case studies and small group findings that demonstrate measurable improvement in articulation and hypernasality have appeared in the literature.<sup>34,35,36,37,38,39,40,41,42,43</sup> Use of electropalatography (EPG), in particular, is an intriguing and promising approach to correction of compensatory articulations in cleft palate. The equipment and the materials cost per case for the customized artificial palate are deterrents. Most of the studies and reports have come from Britain, where the instrumentation was developed. Clinicians and researchers in Japan have also contributed several reports. Preliminary observations suggest that the benefits will be cost-saving over the long-term. There is a need for expansion of instrumental approaches to speech remediation in cleft palate and evidence-based research on their effectiveness. Currently, two of the most viable approaches are electropalatography and videonasopharyngoscopy.

- Research Initiative 6 would aim to establish the efficacy of instrumental biofeedback approaches to speech remediation in cleft palate. Part A of this initiative would involve conducting multiple small group studies on the efficacy of electropalatography in the correction of cleft plate compensatory misarticulations. Part B would involve conducting multiple small group studies on the efficacy of videonasopharyngoscopy in correcting velopharyngeal closure inadequacy in mild/marginal cases of velopharyngeal inadequacy.

In summary, this paper has provided an overview of the impact of craniofacial anomalies on speech. It has addressed how speech and oral structures that support speech should be evaluated in individuals with craniofacial anomalies with a specific focus on cleft lip and palate. Importantly, it has emphasized the importance and efficacy of interdisciplinary team care for this population and the need for improved education and clinical training of both medical and dental students in this specialty area. It has also highlighted ways in which speech-language pathologists in the public schools could be trained and involved in oral health screening and referrals. This clearly is a potential mechanism for reaching children who often are missed and go without care. Six training initiatives have been proposed to increase knowledge and clinical skills among professionals whose jobs are directly concerned with oral health as defined by the Surgeon General's Report on Oral Health in America in 2000.<sup>2</sup>

The remainder of this paper has focused on the need for research concerning team care and needed research initiatives in speech development and treatment in craniofacial populations. Specifically, there is an immediate need for outcomes research, which would validate the economics of team care, as well as patient outcomes of team care. Such outcomes research is mandatory if team care is to survive the changing health care environment. Likewise, there is a paucity of speech outcomes research and there is no national standard by which speech outcomes of physical management for cleft lip and palate should be evaluated. And there are no data on large numbers of patients to demonstrate that speech therapy works. As a response to these and related research needs, six research initiatives have been proposed.

It is hoped that these proposed training and research initiatives will at least have laid some groundwork for the multifaceted task of improving the oral health of children with craniofacial anomalies and other special health care needs.

**Table 1—Orofacial structures and brief indicators of what to look for<sup>43</sup>**

<b>Structure</b>	<b>What to Look For</b>
Lips	<ul style="list-style-type: none"> <li>• competence; length (philtrum); symmetry</li> <li>• frenulum; sulcus (fistulae)</li> <li>• movements for rounding, compressing, spreading</li> </ul>
Nose	<ul style="list-style-type: none"> <li>• anterior patency</li> <li>• inferior patency (bowed septum)</li> </ul>
Dentition	<ul style="list-style-type: none"> <li>• missing teeth; rotated teeth</li> <li>• supernumerary or duplicated teeth</li> <li>• ectopic teeth (location re: speech targets)</li> <li>• diastemas</li> </ul>
Occlusion	<ul style="list-style-type: none"> <li>• overjet, protrusive premaxilla</li> <li>• underjet, with and without Class III malocclusion</li> <li>• open bites (location)</li> <li>• lateral/buccal crossbites; reduced maxillary width</li> </ul>
Tongue	<ul style="list-style-type: none"> <li>• ankyloglossia (anteriorly displaced or shortened lingual frenulum); impact on ROM, precision</li> <li>• relative tongue size</li> <li>• microglossia, glossoptosis and other anomalies occurring in syndromes</li> <li>• symmetry during protrusion, elevation</li> </ul>
Hard Palate & Alveolus	<ul style="list-style-type: none"> <li>• fistulae (always note location and patency):</li> <li>• alveolar/nasolabial</li> <li>• palatal (anterior vs posterior)</li> <li>• submucous clefts</li> <li>-continuum of intraorally-visible findings</li> <li>-can't see occult clefts intraorally</li> </ul>
Velum & Faucial Isthmus	<ul style="list-style-type: none"> <li>• bifid uvula (suspect submucous cleft) absent uvula</li> <li>• velar length; symmetry at rest &amp; during phonation</li> <li>• velopharyngeal gag response</li> <li>• tonsil size and position</li> </ul>

**Table 2—Developmental assessment periods and key orofacial & speech objectives**

<p><b>Infancy/Early Toddler (0 to 18 months):</b></p> <ul style="list-style-type: none"> <li>• assess feeding, babbling, early speech(-like) utterances</li> <li>• assess pre- and post-palatoplasty sound types</li> <li>• provide early speech stimulation activities</li> <li>• compare to normal acquisition patterns and schedules</li> </ul> <p><b>Toddler/Preschool (18 months to 5 years):</b></p> <ul style="list-style-type: none"> <li>• monitor post-palatoplasty velopharyngeal (VP) adequacy</li> <li>• flag troublesome fistulae</li> <li>• document phonetic inventory, compensatory misarticulations, phonological patterns</li> <li>• rate speech intelligibility</li> <li>• determine need for direct speech intervention</li> <li>• flag potential need for secondary surgery</li> <li>• assess speech outcome of early intervention</li> </ul>	<p><b>School Age/Adolescence (6 to 12 years):</b></p> <ul style="list-style-type: none"> <li>• continue to monitor post-op VP speech adequacy</li> <li>• evaluate role of tonsils, adenoid in VP closure</li> <li>• flag and repair troublesome fistulae</li> <li>• determine need for further physical management</li> <li>• evaluate speech patterns in relation to dentition and occlusion</li> <li>• rate speech intelligibility</li> <li>• determine need and efficacy of speech remediation</li> </ul> <p><b>Teenage/Adult (13 years and older):</b></p> <ul style="list-style-type: none"> <li>• monitor post-op speech adequacy, including impact of orthognathic procedures</li> <li>• determine speech adequacy and treatment needs, especially in relation to dental and occlusal status</li> <li>• assess final speech outcome</li> </ul>
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(Note: All references represent Level III of the US Preventive Services Task Force’s Grading of Evidence)

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# Access to Dental Care for Group Home Residents in Iowa

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## Introduction

Developmental disabilities are chronic disabling conditions acquired before a person reaches 22 years of age.<sup>1</sup> They are attributable to mental or physical impairment or a combination of impairments. These conditions include mental retardation, cerebral palsy, epilepsy, autism, and other neurological conditions that result in the impairment of general intellectual functioning or adaptive behavior. Of all developmental disabilities, mental retardation (MR) has the highest prevalence.<sup>2</sup>

For nearly a century, beginning in the mid-1800s, individuals with developmental disabilities commonly resided in state institutions. But beginning in the early 1950s, ideas of centralization and normalization were formulated.<sup>3</sup> In the early 1960s, the Presidents' Panel on Mental Retardation was established, leading to the enactment of numerous recommendations to improve research, prevention, planning, and services for this population.<sup>3</sup> These efforts, coupled with the establishment of Medicare and Medicaid programs in the mid-1960s, made it possible for many individuals with developmental disabilities to secure long-term care, including medical care, in their communities.<sup>4</sup>

The transfer of individuals from state institutions to community facilities became known as deinstitutionalization. When this process began in the 1960s, nearly 200,000 individuals were living in just 165 institutions nationwide. Thirty-five percent of these institutions had over 2,000 residents each.<sup>5</sup> When considered only in terms of physical relocation, deinstitutionalization has been very successful. By 1986, there were 269,954 beds for developmentally disabled clients in 14,639 community-located facilities nationwide.<sup>6</sup> The most common type of community facility is the group home.<sup>7</sup>

The term deinstitutionalization implies more than just the transfer from an institution to a group home. It includes the entire process of shifting social services, health care, and educational needs to a network within each community. Assessing the success of this aspect of deinstitutionalization is more difficult. One area of the deinstitutionalization process that has had only limited success is the provision of oral health care services for these individuals within the community. Many studies have shown that the oral health of individuals with developmental disabilities, although dependent upon many factors, is generally poorer than the oral health of

the general population.<sup>8,9,10,11,12,13,14,15</sup> For example, individuals with more severe disabilities may rely fully upon other individuals for oral hygiene assistance, which may not always be provided routinely. At the other extreme, residents requiring only minimal supervision may have poor oral hygiene habits and poor food selection, resulting in a decline in oral health, even though these individuals have greater functional abilities.<sup>8</sup>

Although complicating factors exist, poor oral health is not biologically linked to any of the developmental disabilities but the type of disability may influence the type and extent of the oral health problem; e.g., Down syndrome may predispose patients to periodontal disease.<sup>15</sup> But with sufficient supervision, proper diet, and some assistance, oral diseases are preventable conditions among those with disabilities. Routine dental care and the use of preventive regimens, such as fluorides, sealants, and routine prophylaxes, can help these individuals maintain a level of oral health comparable to that of the general population.

In the early 1980s, many programs were established in dental schools to train dentists to treat this population. Some programs were limited to didactic training only, while others included extensive "hands on" experiences. Many studies have attempted to evaluate the short-term success of these programs, but these evaluations have often measured only attitudes rather than behaviors. Many dentists report willingness to treat this population, yet in many cases few, if any, patients with developmental disabilities are treated in their practices.<sup>16</sup>

In addition to a lack of dentists' training, there are many other factors that interfere with the receipt of dental treatment by this population. The generally low socioeconomic status of individuals with developmental disabilities poses a significant problem in financing dental care.<sup>12</sup> Physical disabilities and structural barriers in many dental offices interfere with the provision of services.<sup>17</sup> In addition, the inability of patients to cooperate with dental treatment also may limit access to dental care. Lastly, issues of parental consent and legal guardianship further complicate providing care to this population.<sup>12</sup>

Solutions to many of these access issues have been elusive. To improve the access to oral health care for the population with developmental disabilities, a comprehensive understanding of the barriers to care is

necessary. The purpose of this study was to evaluate factors affecting access to dental care for individuals with developmental disabilities residing in group homes in Iowa.

## Methods

A 41-item questionnaire was designed to assess perceived access to dental care for residents of group homes in Iowa and to collect information on characteristics of the homes, their residents, and area dentists that might affect access. To assess perceived access to care (dependent variable), the survey asked group home administrators to respond on a five-point Likert-type scale to the question, "How would you rate your ability to get dental care for clients of your group home(s)?" Response choices included "excellent," "very good," "good," "fair," and "poor."

Characteristics of the homes assessed included licensure, size, location, distance to a dental office, availability of staff to transport clients, and perceived ability of staff to recognize a dental need. Characteristics of the residents assessed included ability to behave at the dental office, ability to communicate a dental need, ability to tolerate treatment in the operating room, and availability of parental consent for treatment. Dentist traits evaluated included perceived willingness to treat developmentally disabled patients, perceived comfort with developmentally disabled patients, participation in Medicaid, and ability to provide treatment in a hospital operating room. Approval from the University of Iowa Institutional Review Board (IRB) was obtained prior to contacting the group homes.

The target population for this study consisted of all group homes listed in *1996 Health Care Facilities in Iowa*, published by the Iowa Department of Inspections and Appeals (n=347).<sup>18</sup> The four types of group home facilities included in this list were Intermediate Care Facilities for the Mentally Retarded (ICF/MRs), Residential Care Facilities for the Mentally Retarded (RCF/MRs), Specialized Residential Care Facilities, and Home and Community Based Waiver Homes (HCBS).

Attempts were made to contact each group home in the state by telephone. Multiple telephone contacts were attempted before a non-response was recorded. During the telephone contact, the primary investigator introduced herself, explained the nature of the study, and assured confidentiality of all disclosed information. The questionnaire was then administered. Information regarding each home was provided by a representative of the home, often the nurse administrator or house manager. Completed questionnaires were reviewed and verified for accuracy and completeness. SPSS statistical software was used for data entry and management.

For evaluation purposes, the RCF/MR homes, Specialized RCF/MR homes, and HCBS homes were collapsed into a single category. These three types of homes were most often run by the same agencies and frequently shared nursing staff among home types. The main differences among these three types of homes were in levels of reimbursement from the state, and not in the services available at each home.

The responses to the survey were weighted based on the number of homes for which each respondent was replying. If a respondent was associated with more than one group home, and if each of these homes had identical issues involving access to dental care, the respondent offered a single response that was then entered into SPSS separately for each of the associated homes.

Cross tabulation tables and chi-square analyses were used to evaluate differences between respondents and non-respondents based on demographic information. Demographics for the non-participating homes were obtained from the Iowa State Department of Inspections and Appeals.<sup>18</sup> Cross-tabulation tables were generated to explore the relationships between dependent and independent variables. Due to the ordinal nature of the dependent variable, correlations with Kendall's tau were used to determine which independent variables were significantly related to access to care, as reported by the responding group homes.<sup>19</sup> The significance level used was  $p < 0.05$ . Chi-square analysis was performed to evaluate differences in perceived ability to get dental care based on demographic characteristics.

All independent variables that displayed a statistically significant relationship ( $p < 0.1$ ) with the dependent variable (perceived ability of the home to get dental care) were evaluated for covariance. Upon elimination of the covariant factors, remaining variables were entered into a linear regression equation. The independent variables entered into the model were first ranked using Spearman's Rank, to compensate for the use of an ordinal dependent variable.<sup>19</sup>

## Results

Participation rates in the survey were high, with 120 group home administrators providing information for 318 group homes (91.6% response). The 318 homes with responses housed 3,150 developmentally disabled individuals. Residing in the 134 ICF/MR homes were 1,400 individuals (10.7 clients/home). The 187 RCF/MR type homes served 1,750 residents (9.4 clients/home).

Survey responses indicated that 95.5% of group home residents received Medicaid benefits. For the 238 group homes that reported the name and distance to the office

of their dentist of record, the mean distance was 8.8 miles (range 0.5 to 70 miles). Most clients were treated by general dentists (79.8% of homes), while 48 (20.2%) had pediatric dentists as their dentist of record. Of the responding homes, 59 (18.6%) had at least one client who received dental treatment in the operating room during the previous year. The average distance traveled for dental care provided in an operating room was 74.2 miles, with a range of 2 to 250 miles.

Responses to the question, "How would you rate your ability to get dental care for the clients of your group home?" served as the dependent variable in this study. Overall, the respondents expressed satisfaction with their ability to get dental care for their clients (Table 1). The vast majority (85.2%) indicated their ability to get dental care for their clients was "good," "very good," or "excellent." Respondents for 47 group homes (14.8%) indicated their ability to get dental care for their clients was either "fair" or "poor."

Questions were also posed that assessed the group homes' compliance with state licensure requirements. Current requirements include retaining a dental record for each resident, having an individualized program plan (including oral health maintenance) for each resident, and providing oral health training for staff on an annual basis. As presented in Table 2, the vast majority of homes were in compliance with the first two requirements, but only 75.5% indicated their staff received annual oral health in-service training. Oral health in-service training for staff that received it was most commonly provided by a nurse, videotape, a hygienist, or a local dentist.

The final section of the survey evaluated possible barriers to dental care for this population, including factors related to the local dentists, the clients, and the group home or its staff. Responses were given on a five-point Likert-type scale of how strongly the respondents agreed or disagreed with each statement. The majority of the respondents expressed strong agreement or agreement with statements concerning two of the four client factors, and all of the dentist and group home factors (Table 3).

Cross tabulation tables were employed to assess the association of the independent variables with the main dependent variable. The strength and order of association between the variables was determined using Kendall's tau, a measure of order association for ordinal variables. Twelve independent variables were found to be significantly associated with perceived access to dental care (parental consent for treatment was included at  $p=0.059$ ) (Table 4).

Linear regression was used to create main effects models describing the joint associations between the independent variables and the perception of respondents about their ability to get dental care for their clients. Each of the twelve independent variables significant in the bivariate analyses and the main dependent variable were first ranked using Spearman's rank to account for the ordering of both variables. Analysis of correlations between all independent variables revealed an interaction between "perceived comfort of the local dentist" and "perceived willingness of the local dentist to treat this population." The latter variable was excluded from the regression equation to eliminate this interaction. The model predicted 46.0% of the variance in the dependent variable (Table 5).

Of the 12 factors included in the model, only four were significantly associated with access to dental care for the population of interest. A group home had a lower probability of having access to dental care for its residents if the survey respondent perceived the local dentists to be uncomfortable with treating patients with developmental disabilities ( $p<.001$ ), felt that local dentists would not accept Medicaid reimbursement ( $p=.016$ ), perceived the dental office as too far away ( $p<.001$ ), or considered the local dental offices as not wheelchair accessible ( $p<.001$ ).

## Discussion

The findings of this study were consistent with those of some previous studies but not consistent with some others. This study found that problems with perceived access to dental care for the developmentally disabled population living in group homes were relatively uncommon. Only 47 homes (14.8%) reported their ability to get dental care was fair or poor.

Discussions with respondents for these homes revealed that group home representatives felt the primary problem in access was dentists' refusal to accept Medicaid patients. Respondents felt that many dentists were willing to treat existing Medicaid clients but were not accepting new Medicaid patients. In problem areas, group homes faced access problems with each new client. Some homes in the northwest part of the state found a solution to this problem by taking clients out of state for treatment.

This study found a statistically significant difference between the ICF/MR and RCF/MR homes in their ability to access dental care. This difference was expected, and the primary explanation for this difference is that RCF/MR residents are generally of much higher function. This finding suggests that the severity of the disability can influence access to dental care, although this study used the group home as the unit of measure

rather than the individual. A study that evaluates access to care based on characteristics of the individual client is needed to evaluate more accurately the effect of the severity of the disability on access.

This survey evaluated how known barriers to dental care affected the study population. It was determined that factors related to dentists and dental practice characteristics were most often associated with perceived barriers to access to dental care for the persons with developmental disabilities. Group home staff characteristics and the clients' traits affected perceived access to care to a lesser degree. This finding may be due in part to the study design, which included only group home personnel in the survey. These individuals may be less likely to perceive themselves, their staffs, or clients as contributing to access problems.

The two main problems with access to dental care echoed repeatedly were the comfort of dentists in treating this population and low dentist participation rates in accepting new Medicaid patients. Many respondents perceived the dentists as being uncomfortable or even fearful of their clients. Respondents often mentioned that health care providers in general (physicians as well as dentists) were not confident in treating their clients.

The association between access to dental care and wheelchair accessibility of the offices can be viewed in two different ways. One can consider the physical difficulties encountered when transporting a wheelchair bound patient to an office that is not wheelchair accessible. This can be reason enough for avoiding or postponing dental visits. Caution must be used in interpreting this result, however, because homes with true difficulties in accessing dental care often do not

ever get to the dental office and are refused care for their patients over the phone.

Finally, homes with difficulty accessing dental care are likely to feel that the dental office is too far away. This association can be explained by the fact that when a dentist refuses to treat residents of a group home, they are forced to contact other dental professionals, often in distant towns or areas of greater population.

### Conclusions

This study evaluated factors that influence access to dental care for developmentally disabled individuals residing in group homes in Iowa. In a multivariate analysis, four factors were found to be significantly associated with a report of poor access to dental care. Group homes reporting poor access to dental care were more likely to report that: 1) local dentists were uncomfortable treating developmentally disabled patients; 2) local dentists would not accept new Medicaid-enrolled patients; 3) dental offices were too far away; and 4) dental offices were not wheelchair accessible.

**Table 1—Ability to get dental care for group home clients**

Response	n	%
Excellent	107	33.6%
Very Good	111	34.9%
Good	53	16.7%
Fair	33	10.4%
Poor	14	4.4%
Total	318	100.0%

**Table 2—Responses related to compliance with licensure requirements**

Task	Yes		No		Sum Total	
	#	(%)	#	(%)	#	(%)
Retain Dental Record	316	(99.4)	2	(0.6)	318	(100)
Has Individual Program Plans	313	(98.4)	5	(1.6)	318	(100)
Oral Health Training for Staff	240	(75.5)	78	(24.5)	318	(100)

**Table 3—Factors effect on access to dental care**

	Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree	
	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
<b>CLIENT FACTORS</b>										
Clients behave in dental office	44	(13.8)	127	(46.2)	35	(11.0)	73	(23.0)	19	(6.0)
Clients can communicate a dental need	14	(4.4)	116	(36.5)	15	(4.8)	89	(28.0)	84	(26.4)
Dental treatment in the OR is hard on clients	14	(4.4)	95	(29.9)	95	(29.9)	87	(27.4)	27	(8.5)
Parents always give treatment consent	132	(41.5)	148	(46.5)	5	(1.6)	31	(9.7)	2	(0.6)
<b>DENTIST FACTORS</b>										
Dentist is willing to treat GH clients	83	(26.1)	118	(37.1)	52	(16.4)	47	(14.8)	18	(5.7)
Dentist is comfortable with DD patients	55	(17.3)	126	(39.6)	40	(12.6)	81	(25.5)	16	(5.0)
Dentist accepts Medicaid	49	(15.4)	175	(55.0)	20	(6.3)	31	(9.7)	43	(13.5)
Dentist provides treatment in the operating room	43	(13.5)	163	(51.3)	48	(15.1)	38	(11.9)	26	(8.2)
Dental office is wheelchair accessible	95	(29.9)	158	(49.7)	20	(6.3)	30	(9.4)	15	(4.7)
<b>GROUP HOME STAFF FACTORS</b>										
Dental office is close to group home	69	(21.7)	203	(63.8)	10	(3.1)	23	(7.2)	13	(4.1)
Home has enough staff to transport clients	96	(30.2)	192	(60.4)	3	(0.9)	19	(6.0)	8	(2.5)
Staff can recognize a dental need	73	(23.0)	216	(67.9)	22	(6.9)	7	(2.2)	0	(0.0)

**Table 4—Factors Associated with Reported Access to Care (Bivariate Analysis)**

<b>ACCESS FACTOR</b>	<b>Kendall's Tau</b>	<b>P Value</b>
<b>CLIENT TRAITS</b>		
*Client's ability to behave at dental office	.138	.004
*Client's ability to communicate dental need	.347	<.001
Client's ability to tolerate treatment in OR	.051	.322
Parents agree to consent for treatment	.093	.059
<b>DENTIST TRAITS</b>		
*Perceived willingness of dentists to treat DD	.423	<.001
*Perceived comfort of dentist with DD patients	.497	<.001
*Dentist participation in Medicaid	.339	<.001
*Dentist offer treatment in operating room	.100	.034
*Dental office is wheelchair accessible	.285	<.001
<b>HOME TRAITS</b>		
*Distance to dental office is minimal	.478	<.001
*Home has enough staff to transport clients	.130	.015
Perceived ability of staff to recognize need	.059	.252
<b>DEMOGRAPHICS</b>		
	<b>Chi Square</b>	<b>P Value</b>
*Licensure of group home	13.29	.008
*Size of group home	18.4	.018
*County of group home	54.1	<.001
Agency owned home	3.51	.476

\*significant factor at p<.05

**Table 5—Factors Associated with Reported Access to Care (Results From Linear Regression Model)**

Factor	$\beta$ Coefficient	Standard Error	p Value
<b>DENTIST TRAITS</b>			
*Perceived comfort of dentist with DD patients	.345	.058	<.001
*Dentist participation in Medicaid	.126	.052	.016
Dentist offer treatment in OR	-.003	.053	.958
*Dental offices are wheelchair accessible	.166	.048	<.001
<b>HOME TRAIT</b>			
*Distance to dental office is minimal	.261	.064	<.001
Home has enough staff to transport clients	.024	.060	.660
<b>CLIENT TRAITS</b>			
Client’s ability to communicate a dental need	.102	.057	.074
Parents agree to consent for treatment	.021	.050	.657
Clients are disruptive in the office	-.030	.058	.600
<b>DEMOGRAPHICS</b>			
Licensure of group home	-2.53	4.72	.593
Size of group home	-2.90	6.23	.642
County of group home	1.95	9.11	.831

R<sup>2</sup>=.460

\*=significant at p<0.05

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# Access to Care: A Clinical Perspective

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Beginning in the late 1960s, children and adults have been gradually but steadily moved out of large state institutions for people with disabilities.<sup>1,2</sup> This effort has been to provide for “normalization” of these people and to improve the quality of their lives. Now all but a relatively few children and adults with neurodevelopmental disabilities and other special care health needs are out of institutions and are seeking oral health care through community resources. Many of the children and adults remaining in large state institutions for people with developmental disabilities are waiting for the opening of additional appropriate community-based facilities such as group homes and other less restrictive living arrangements.

All states have significantly reduced the institutional population and some have closed the institutions. State and community planners expected that the health care of these deinstitutionalized people, as well as those who had always lived in the community, would be integrated into the existing health resources in the community. In respect to oral health services, the integration into the community has been severely limited in most communities.<sup>3,4</sup> There are certainly areas of acceptable levels of access to oral care, but this situation is the exception rather than the rule.

If all oral health care factors had developed in an optimum way, the following scenario would illustrate the standard in oral health care. A mother and father would bring their 10-month-old Down syndrome son to a dental office for his first appointment with a dentist. In many areas of the United States, this dentist is likely to be a pediatric dentist. The parents would know to do this as a result of prenatal counseling and, in addition, their pediatrician or family practice physician would have referred this 10-month-old child for a dental examination and preventive oral care as recommended by the American Academy of Pediatric Dentistry.<sup>6</sup> Perhaps the physician might have already applied fluoride varnish to the child's teeth, as is being done today in some pilot project medical offices in North Carolina.<sup>7,8</sup> Or perhaps they sought care because they agree with the ARC statement “...All people with mental retardation, regardless of the degree of their disability, have a right to appropriate, affordable and accessible medical and dental treatment throughout their lives as a part of a nationwide, universal health care system.”<sup>9</sup>

The child would be examined by a well-trained dental staff and, based on risk factors associated with this particular child, would be provided with anticipatory guidance in preventing oral disease. The dental team would be aware of family dynamics and family points of view that often influence families with children with

special health care needs. The team, including all staff members, would know how to integrate this preventive program within constraints that are likely to be encountered in a family that has a child with Down syndrome.

The family would depart this appointment with knowledge of how to promote good oral health and a determination that their child can and will have good oral health. They will follow through with a prescribed plan that will prevent, or at least quite significantly limit, oral disease in their son. They will return for regular preventive appointments where the best practice preventive procedures will be provided for their child. These procedures would, of course, be tailored to this individual child based on an assessment of disease risk for this particular child.

Through the months and years of returning for preventive recall appointments, the child will be desensitized to the surroundings and people of the dental office. He will learn to be a competent dental patient who actively cooperates with prescribed dental procedures.

The dentist and staff involved with this child will have been trained in techniques and procedures appropriate to the needs of this child. In addition, the training will have included experiences that lead to valuing children and adults with special needs. The training will also have included experiences that lead to understanding the dynamics of a family with a Down syndrome child. Though this understanding, the dentist and staff will be able to prescribe and help implement an anticipatory guidance plan that will take into account these dynamics and result in optimal oral health for this now young adult. This young man is now likely to be ready for new experiences that may include living outside his family's home in a more independent living arrangement. When he grows into adulthood, he will need to move from his pediatric dentist to a dentist experienced in caring for adults and who keeps up with current knowledge related to adult oral health issues. As a result of experience with dental care, this young adult will have an easy time in the transition to a new dentist who can continue to provide best practice dental care and preventive therapy.

The new dentist and staff will have been trained in all matters related to caring for adults with special needs. They will now work with caregivers that have replaced parents in providing support and guidance to this young man. These caregivers may include a group home staff and community access personnel who now are responsible for helping follow through with prescribed preventive or therapeutic oral health programs. These caregivers have regular and repeated training on oral health issues and techniques.

The dental teams have been adequately compensated all the while that they have been providing oral care for this person with Down syndrome. The skill, time, and resources required for providing care to this person have been recognized by third party payers, and the payers embraces the notion that prevention is better and cheaper. There are pockets of the country where this scenario is played out as routine. But the general status is that this optimum situation is the exception, leaving many children and adults with special needs far short of the care that is required for optimal oral health.

Why does the child with Down syndrome described earlier not get the care described? What are the barriers to getting this level of care? They can be divided into five key areas.

1. Primary medical care system
2. Parents of the child
3. The child
4. The dentist
5. Payment for care

### **Primary medical care system as a barrier to care**

Frequently, the physicians and other health care providers fail to include oral health in the overall plan for the child. This can happen as a result of a variety of factors, but most noteworthy among them is the limited training most physicians get regarding oral health. Parents depend on them as well as other providers, such as a psychologist or physical therapist, to tell them how to care for their child with special needs.<sup>10</sup> Parents know their child has to be treated in different and special ways, but are not certain what these are.<sup>11</sup> They depend on the professionals to tell them what they are to do for their child. If oral care is not included in the plan, then parents are not as likely to seek or provide oral care for the child.

Clinical experience indicates that if parents know what to do and how to do it, then they tend to carry out oral health recommendations effectively. Someone early on in the primary health care of the child must stress that oral health is a priority and will be of high value to the child and to the child's parents. They must know and believe that most problematic oral diseases are preventable and they can improve the quality of their child's life by taking advantage of what we know about controlling oral diseases.

### **Parents as a barrier**

Parents of children with significant disabilities may have an outlook on their child that leads to practices that may promote oral disease or avoidance of dental care. A parental dynamic that has been described as "chronic

sorrow" may lead to feelings of denial of the severity of their child's problems, guilt feelings of responsibility for having the child, and even anger toward health care workers who want to help with the child.<sup>5,12</sup>

Parents can have a direct influence on oral health in a variety of ways. The parents may indulge the child by offering an unhealthy diet to the child that may placate their guilt feelings. Parents may fail to take their child for care because they fear that dentists who know how to care for their child are unavailable. They may even fail to seek dental care for their child because they themselves may fear going to the dentist, and as a consequence, do not want to put their child in a situation that they avoid themselves. Some parents who have a child with behavior problems or who looks significantly different may have difficulty taking their child to public places such as a dental office.<sup>13</sup>

### **The child as a barrier**

The child's ability to aid in oral care ranges from being able independently and effectively to take care of oral health completely to needing others to brush and floss teeth while vigorously avoiding care of any kind. The wide spectrum of behavior makes it essential that a variety of treatment modalities be available that range from routine treatment in a dental chair to use of a general anesthetic. The range in ability of the child or adult patient to participate in the oral care makes it necessary for the dental team to have a range of treatment techniques and skills.

Getting to a scheduled dental appointment may be a problem for many people with disabilities. Their general level of health may be fragile and frequently cause them to be too ill to go to a dental appointment, thus requiring them to cancel or break dental appointments. A person with a significant disability is dependent on someone to get them to care using a transportation system that may be inadequate or susceptible to many obstacles. These factors as well as others can come together to make canceled and broken appointments a problem.

### **The dentist or dental team as a barrier**

The dentist may choose not to treat children with special health care needs for a variety of reasons.<sup>14</sup> They range from lack of training to the belief that there is someone else to do it. Because of lack of training, the dentist may not recognize the wide range of ability that exists in any category of disability. Some patients can be assimilated into routine care, while others require very specialized skills and training. Some pediatric dentists have stated that they find it difficult to integrate adults with disabilities, especially those who are disruptive, into a practice that includes many young children.<sup>15,16</sup> They try to refer these patients and avoid accepting new adult patients.<sup>17</sup>

While the law relating to the Americans with Disabilities Act may significantly affect dental care, it does not assure that children with special health care needs are appropriately treated or even treated at all.

### **Payment system as a barrier**

The payment system can be a severe barrier to care for children with special health care needs. Nearly all states provide comprehensive dental care to these children through the Medicaid system. Many states provide similar care to adults with disabilities. There are states that accept the responsibility of paying fair compensation for dental care, while others pay as little as 25% of the usual and customary fee—a fee well below the 50-65% overhead rate attributed to many treatment procedures. The low payment rates discourage many dentists from accepting Medicaid patients for treatment. Thus, since most children with special health care needs are eligible for dental care under Medicaid, they are shut out of care unless they have some additional payment support.<sup>18</sup>

Many are concerned that merely raising the payment level will not solve the problem. They are concerned that dental practices have developed and flourished without accepting patients eligible for Medicaid, and they may not recognize a need or responsibility to begin to serve this population. Many expect that a major profession-wide effort will be required to bring dentists to the point of recognizing the responsibility of providing dental care to patients eligible for Medicaid.

To deal with the barrier issues, a broad approach is required. Every state and community has its unique set of strengths and weaknesses that relate to available resources, geographical features, and population distribution. An approach that works in one area may not be able to be transferred to another, but knowledge and principles developed in one area may be very helpful in another place.

Any effort that will improve access to care for children with special health care needs depends on development of an adequate dental health work force trained to meet the preventive and therapeutic needs of this population. Along with development of this work force is the need to enhance oral health training of primary care physicians and other health care professionals who are likely to be interacting with children with special needs. Through this training, they will learn the issues affecting oral health and will come to value oral health for their patients. They will also be more likely to include oral health measures in their treatment plan and will make dental referrals for their very young patients. Also, any effort that will improve access to dental care depends on practitioners receiving fair compensation for their work.

This job requires more skill, training, and time when compared with working with children and adults who do not have special needs.

Several approaches to dealing with access to care issues have been suggested or implemented in a variety of settings.<sup>19</sup> These have met with varying degrees of success and have their advantages and disadvantages. A few approaches will be listed and briefly described.

### **1. Outpatient programs at existing facilities for people with developmental disabilities.**

The dental clinics at institutions that have been downsized or closed are frequently left with a dental staff of knowledgeable, skillful, and caring professionals who provide direct care for patients with disabilities. They also provide support and training for community practitioners who provide care for people with disabilities.<sup>20</sup> In a number of states, this cadre of institutional dentists is being successfully employed as teachers and direct care providers who significantly improve the access to care in their region. While going to the institution for dental care may not fit well with the concept of normalization, it may get the job done in increasing access to dental care. These highly skilled institutional dentists can also go out into the community and provide training through courses and in-office demonstrations of dental treatment techniques.

### **2. Collaboration between university and regional dental clinics for people with disabilities**

Tufts University has had a long-standing Mutual Access Program<sup>21</sup> that provides for direct care and dental training at regional centers. The training extends to dental professionals as well as daily caregivers. Other states are considering this community and dental school collaboration. This approach has the advantage of using the university as a resource while simultaneously getting dental care and training into the community where access to dental care is limited.

### **3. Mobile unit programs**

Several programs have been instituted where a dental team goes to a facility where there are special needs patients. Sometimes these programs combine both special needs patients with disabilities and geriatric patients. A good example of such a program is Access Dental Care, operating in Greensboro, NC.<sup>22</sup> This program serves nearly all the people living in group homes in the countywide metropolitan area. The dental van pulls up at a group home day center, for example, where several group homes may have clients. The portable equipment is set up and appointments are met. Appointments are arranged through a central office where records are kept and the general business of the

program is carried out. The program has access to hospital facilities and can provide a full range of services as determined by the patient's needs. Financial support for this non-profit corporation is primarily through Medicaid fees and some grant or private support.

#### **4. Donated dental services**

This program is operated through the Foundation of Dentistry for the Handicapped.<sup>23</sup> Dentists donate their services in their private offices. The program provides care to special needs patients who cannot afford to pay for treatment. Some dentists in the program reportedly offer to treat as many as five patients each year. The program includes specialists as well as general practitioners.

#### **5. Managed care as a factor in access to care**

Managed care systems are designed to provide access to health care, while at the same time controlling the cost of care.<sup>18</sup> These programs in general have been useful in slowing the growth rate of medical costs and have become commonplace in financing medical care. They have not been as pervasive in financing dental care, but a number of states are developing managed care programs that involve the care of people with disabilities.

From the point of view of the organization paying for the managed care program and the providers, the most desirable situation is enrolling large numbers of healthy people requiring little care. In addition, it is to their advantage to enroll people who seek a limited amount of care. These factors are especially relevant if the funding is on a capitation basis rather than fee for service.

Since children and adults with disabilities are at greater risk for dental disease, and because many programs involving this population mandate regular dental exams and treatment, they are more likely to need and seek dental care than the general population. And when they do seek care, they are likely to require more treatment time per dental procedure, a factor often not fully accounted for in managed care programs.

Because the needs and demands of children with special health care needs in managed care programs often are contrary to factors that make managed care systems financially successful, it is crucial to the oral health of people with developmental disabilities that these programs take into account the differences in their care demands. Oregon is one state that has recognized the differences in care for people with disabilities and has made capitation reimbursement rates significantly higher for people with disabilities.<sup>24,18</sup>

It appears inevitable that the oral care of some children with special health care needs will be through managed care programs. It is also evident that the requirements for care of people with special health care needs and the financial forces driving dental managed care programs compete in many aspects. This competition makes it essential to institute effective and appropriate quality assurance programs that will be vigilant in keeping oral health outcome measures high. As stated by Waldman: "Whether it will be managed 'to care' or 'not to care' will depend on our willingness to expend needed resources for children with special needs and continued vigilance to ensure the delivery of needed health services."<sup>18</sup>

#### **Final thoughts**

For some time, we have known that the more common oral diseases, dental caries, and periodontal disease, are essentially preventable. We know that without effective prevention special needs children and adults are at high risk to develop these diseases. Furthermore, once diseases occur, treatment is more costly and harder to access.<sup>25</sup>

We know that for optimum prevention to occur the prevention practices must begin early in life, be life-long and recur daily. Optimum oral health for children and adults with special needs depends in part on health care providers outside of dentistry. These people, such as physicians, nurses, and group home personnel, must know how the common oral diseases are prevented and must give appropriate priority to those preventive measures. Health care providers outside of dentistry often have frequent contact with people with special needs, making it possible for them to monitor oral health and assure that dental care is receiving appropriate attention.

Considering the whole range of people with special needs, we know that they will require a work force with targeted training for this population. We know that the number of people in the workforce is inadequate. Dental schools and other training programs must address this workforce deficiency.<sup>26</sup>

The cost of oral health care for special needs people and compensation for dental teams providing the care is a nationwide problem. While there are some areas of success, in much of the country the additional costs associated with treating special care patients have not been recognized. The very low rate of compensation for special needs patients supported by Medicaid discourages many dentists from treating these patients. Creating a means of paying for care that recognizes the important differences in special needs people is crucial to improvement of access to care for this group.

There are apparently pockets of excellence in access to dental care. Some programs are providing a high level of both preventive and therapeutic care. Our job is to identify these programs, find out what makes them effective, and where possible, develop similar programs in other settings. Very little investigation has looked at oral health outcomes of the variety of programs that have been in operation. Rigorous investigation measuring oral health outcomes is essential to assuring that programs work and are of value in improving oral health.

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