The Life of a Child: The Role of Family and Community in Children's Oral Health
Views from the NIH and other Federal Agencies (CDC, HRSA, etc.)
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In the preface to *A National Call to Action to Promote Oral Health* (USDHHS 2003) Surgeon General Richard H. Carmona stated:

> "The great and enduring strength of American democracy lies in its commitment to the care and well-being of its citizens. The nation's long-term investment in science and technology has paid off in ever-expanding ways to promote health and prevent disease. We can be proud that these advances have added years to the average life span and enhanced the quality of life. But an "average" is necessarily derived from all values along a continuum and it is here that we come to recognize gaps in health and well-being. Not all Americans are benefiting equally from improvements in health and health care. America's continued growth in diversity has resulted in a society with broad educational, cultural, language, and economic differences that hinder the ability of some individuals and groups from realizing the gains in health enjoyed by many. These health disparities were highlighted in the year 2000 Surgeon General's Report: *Oral Health in America* where it was reported that no less than a "silent epidemic of oral diseases is affecting our most vulnerable citizens—poor children, the elderly, and many members of racial and ethnic minority groups."

His words acknowledge the progress made and challenges still before us in promoting our children's oral health.

My presentation highlights the opportunities and the challenges of federal agencies to address the role of the family and the community in children's oral health.

What are the assumptions for this presentation?
My comments are based on several assumptions: 1) programs directed towards the role of family and community are best designed, implemented and assessed at the local level; 2) while most of the federal activities focused on the nation's health and welfare reside in the Department of Health and Human Services (DHHS), all federal departments have a critical role to play in the health of children, their families and their communities; 3) federally supported activities and programs are not designed to provide consistent support at the local level; and 4) the federal government is but one partner, albeit an essential one, of many partners that need to work together in addressing this topic.

What is the role of the federal government?
When it comes to personal issues, such as issues related to families and our communities, the position of the federal government is a delicate one. In the National Research Council and Institute of Medicine's report, *From Neurons to Neighborhoods,* it is recognized that "..as a public issue, questions about the care and protection of children confront many of the basic values that have defined our country from its founding – personal responsibility, individual self-reliance, and restrained government involvement in people's lives.(NRC/IOM 2000)" The report calls for "rethinking of shared responsibility for children and strategic investment in their future."

Clearly the most critical issue involved in "rethinking of shared responsibility for children" will require continual monitoring and tuning of the federal role. Changes will need to be made via legislative channels. Additionally an effective process for maneuvering the bureaucracy among

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and within federal agencies will be needed. The cabinet heads/departments of the federal government, as part of the Executive Branch, enforce the laws, help execute policies and provide special services according to their current structure. There is no single department dedicated to children, rather child issues are addressed by most departments. While the nation's health is addressed in most of the departments, DHHS is the principal agency focused on health protection and its budget represents about a quarter of all federal outlays. DHHS programs include health research, health care services, professional and public education, medical preparedness and more. It is estimated that one in four Americans receive benefits from Medicaid and Medicare together. However, to "rethink" federal responsibility we need to involve all relevant departments, at a minimum including the Department of Education, US Department of Agriculture, Department of Labor, Department of Justice, Department of Defense and Department of Commerce.

What are some DHHS federal government examples that address children's oral health and the role of families and communities?

Examples of children's oral health programs that include families and/or communities vary from DHHS agency to agency, with the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS) supporting the majority of the federal programs in this category due to their missions. Increasingly National Institutes of Health (NIH) initiatives are encompassing the role of families and communities, and the National Institute of Dental and Craniofacial Research (NIDCR) is actively involved. Even so, many programs are tailored to a specific intervention (sealants, water fluoridation), a single disease (Early Childhood Caries (ECC)), a component of a population (rural, Native Americans, underserved) or on a targeted research question. This "tailoring" may be due to the unique mission or legislative base of an agency, due to "communication" barriers among disciplines needed to address the larger role or due to other factors. However, the call for involvement of families and communities is evolving and programs exist.

A summary of selected DHHS oral health activities of relevance to the *"Call to Action"* was developed to facilitate partnering within and beyond the federal government and to identify gaps for planning purposes. To access this summary inventory, go to www.phs-dental.org and access the "National Call to Action to Promote Oral Health website" button on the left column at the bottom. *"A National Call to Action to Promote Oral Health,"* released on 2003, provided a template of actions that, if addressed, would benefit the nation's oral health. These actions include: changing perceptions of oral health; overcoming barriers by replicating effective programs; building the science base and accelerating the transfer of science into action; increasing oral health workforce diversity, capacity and flexibility and increasing collaborations. Professional organizations, academic institutions, the private sector and governments (national, state, local and tribal) have taken a range of steps to address these actions and the development of a national oral health coalition is in its initial stages. The following examples reference some of relevant listed activities and also highlight more recent activities:

CDC's activities cover a broad array of topics (www.cdc.gov). Of critical relevance to this conference are the CDC Division of Oral Health's state oral health cooperative agreement infrastructure program and the "Best Practices" project with ASTDD, and CDC's support of

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systematic reviews of community preventive services. The cooperative agreement program provides states with funds to strengthen their oral health programs with a focus on reducing inequalities. The Best Practices project has inventoried existing programs, most of which target children, with a focus on those addressing the Healthy People 2010 health promotion and disease prevention objectives. CDC has spear-headed the design and application of systematic review of the literature for community based programs, an effort that has resulted in The Guide to Community Preventive Services, developed by the Task Force on Community Preventive Services. For example, the Task Force recommended water fluoridation and school-based and school-linked dental sealant programs on the basis of strong evidence of effectiveness in preventing dental caries.

HRSA has a range of oral health programs of relevance to children's oral health across its' Bureaus (www.hrsa.gov). Families and communities are routinely considered in the programs supported by the Bureau of Maternal and Child Health. A recent (May 2006) workshop on ECC sponsored by this Bureau, identified lessons learned for preventing and reducing this complex disease and recognized the critical role of reaching out to families, providers, communities and to issues of program sustainability and flexibility. The workshop concluded that community input is critical to ECC program design and development and the example given was the approach used by Washington State's Cavity Free Kids program that conducted focus groups with parents and teachers during the initial planning phase. The workshop also noted that building broad support for ECC programs is necessary and requires intensive lobbying and networking with a diverse group of stakeholders. Networking challenges relate to fragmentation and competition among agencies serving maternal and child populations who often have to compete for limited resources.

In FY2005 NIDCR supported a little more than $60M on children's research, covering a full range of diseases and conditions (www.nidcr.nih.gov). NIDCR's five Centers for Research to Reduce Oral Health Disparities are an example of a research initiative focused on children and their caregivers. Now in their fifth year they are providing tangible outcomes of key relevance to this conference. A recent summary of the Centers' progress was summarized at the May 2006 Council meeting. Four of the centers focus on ECC and one on oral cancer. They have undertaken over 30 studies, including nine intervention studies, seven of which were randomized clinical trials. Two of the studies were recently published in the Journal of Dental Research highlighting the efficacy of fluoride varnish in low-income, racially and ethnically diverse children (Weintraub 2006) and the caries preventive properties of xylitol (Milgrom 2006). The studies from the Centers are developing new methods, such as quality of life measures for young children and adolescents in multiple languages and software to enhance cultural sensitivity of dental providers. Also Center studies are extending beyond the usual factors and exploring aspects of family dynamics, social factors including neighborhood characteristics (Tellez 2006) and the study of the effects of trace elements.

How is the federal funding of research programs addressing families, communities and health?

This conference provides an opportunity to discuss how to integrate all aspects of society that support and nurture children and to discuss positioning oral health so it is seen as "one of many important outcomes." Increasingly NIH and other PHS research initiatives are stimulating

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opportunities for the support of multi- and inter-disciplinary research, which in turn will provide the evidence base for programs.

Examples of current research initiatives that include NIDCR sponsorship (These can be accessed at
http://www.nidcr.nih.gov/Funding/CurrentFundingOpportunities/ProgramAnnouncements/default.htm ; click Behavioral and Social Science, and Health Literacy) and include:
Understanding and Promoting Health Literacy (PAR-06-132, PA-04-116)
Community Participation in Research (PAR-06-247, PAR-05-026)
Social and Cultural Dimensions of Health (PA-05-029)

A research agenda for oral health literacy provides a guide to investigators as they explore this new area of science (Workgroup Report 2005).

Concepts presented to the May 2006 NIDCR council included a concept to reissue the solicitation for Centers for Research to Reduce Oral Health Disparities, and two new health promotion research concepts. One of the latter concepts proposes health promotion research directed to improving the oral health of women and their infants with a focus on women before, during and after their pregnancy. The other is a program announcement concept that calls for research across the life span. Both concepts stress the objectives of applying or adapting existing, or developing new, behavioral theories and planning research models to known risk factors and lifestyle aspects of oral diseases and conditions; promoting optimal oral health of individuals, families and communities in the context of overall health and co-morbidities, and integrating oral health promotion into general health promotion programs.

Other examples where dental research is not yet involved, but where new knowledge may emerge, include:
Understanding Mechanisms of Health Risk Behavior Change in Children and Adolescents (PA-04-121)
School-based Interventions to Prevent Obesity (PA-04-145)
Parenting Capacities and Health Outcomes in Youth and Adolescents (PA-06-0998 and PA-06-097)

What are the challenges for the federal government in incorporating families and communities in addressing children's oral health needs?
Programs of relevance to children are found throughout the federal departments. Taking advantage of the federal programs will require integrating programs within and beyond agencies. This is a major challenge, but is surmountable. A successful example is the collaboration between HRSA's Bureau of Maternal and Child Health and the Office of Head Start, Administration of Children and Families (ACF). This program focuses on oral health access, prevention and education of Head Start children and on interactions between Head Start programs and communities. Issues that emerge with these collaborations relate to changing program priorities, stability of key staff, and unique aspects of funding mechanisms. While HRSA and ACF have different missions they both provide technical assistance for state and local programs. The test for establishing collaborations across agencies will come when agencies are able to negotiate partnerships among programs with different missions, such as research and

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service. (Note: In another field, cancer and heart research, this has happened in the realm of collaborations between the Centers for Medicaid and Medicare Services and NHLBI and NCI for the support of clinical trials.)

The traditional operations of the federal government may present another challenge. NIDCR addressed another challenge that included modifying its funding mechanisms, when it undertook research related to minority health and health disparities. Given the nature of addressing research that requires community input and partnerships it was realized that the funding mechanism used needed to provide funds for a longer period of time than usual (seven, versus the usual five years for large grants) and to permit opportunities to explore new studies. Even with these modifications, concerns about program sustainability and needed related services remain.

Fragmentation of oral health programs throughout the federal government remains a challenge. There have been several studies that have critically looked at the status of oral health programs within DHHS (USDHHS 1989, SysteMetrics, Inc. 19940. The 1989 report called for increasing the capacity of agencies to provide dental expertise to programs that can enhance oral health, and also led to the creation of a trans-agency oral health coordinating committee (go to www.phs-dental.org and access the PHS OHCC (Oral Health Coordinating Committee) button on the left). Communication is the primary function of this committee, but also it has resulted in a convenient way to develop and provide input to national endeavors such as health data collection, or to input related to the Healthy People health promotion and disease prevention objectives.

Interactions among the many levels of government require attention. A variety of diverse relationships exist between the federal government and state, county, local and tribal governments. Communication, coordination and roles and responsibilities need to be routinely assessed. Scott Tomar's assessment of the dental public health infrastructure provides insight to the needs of aspects of government capacity and includes human and fiscal resources among others (Tomar).

Other challenges, not unique to the federal government, include:

- Integrating oral health into overall health or health determinant programs
- Maintaining a balance between a focus on health promotion, disease prevention and disease management
- Incorporating evaluation into programs
- Balancing dependence on government with responsibility of individuals, families and communities

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What is basis for the federal government involving families and communities in addressing children's oral health needs?

The public health and health policy community has been well informed of the scope of factors that affect health. The WHO's definition of health in 1948 expanded the definition to include a complete state of "physical, mental, and social well-being and not simply the absence of infirmity." This opened the door to considering the effects of quality of life, individuals in the

context of daily living, and considering interactions with families and communities and in social and civic interactions. The models of public health were expanded in the 1970s with the Lalonde Report, or the Health Field Concept (Lalonde 1974) that emphasized that lifestyle and environment were of critical importance together with human biology and organization of health care. These four determinants then formed the basis of the Ottawa Charter for Health Promotion (WHO 1986) that proposed five actions that are needed beyond health care and home care: creating healthful environments; building health public policy, strengthening community action, developing personal skills, and reorienting health services. The United States' national health promotion and disease prevention objectives have established a process and outcomes that provide an imperative for integrating all sectors affecting health (DHHS 2000).

Why should the federal government do this?

The federal government provided the funding for documenting the oral health status of children, for increasing our knowledge of the effects of oral diseases and conditions on their lives, and for developing effective interventions to prevent oral diseases and promote oral health. With this information the federal government has the imperative to actively coordinate and stimulate action.

Basically the incentive for the Federal government to take action in involving families and communities in addressing children's oral health needs, and in oral health in general, is to obtain a more successful return on its investment. Our progress towards the Healthy People 2010 objectives (DHHS 2000) demonstrates that there is much room for improvement (http://www.healthypeople.gov/data/2010prog/focus21/). The numerous objectives give visibility to the complex and far-reaching interactions needed among multiple factors. We may need to consider the development of different indicators and outcomes. The effects of unprevented and untreated oral disease and conditions in children affects their ability to learn, affects their social development and causes them unnecessary pain and discomfort. In addition, the outcomes may or may not reduce the cost of our federal investment in promoting the health of children, but instead we may need to look at outcomes with economic, social and ethical implications.

Where do we go from here?

As an integral part of the nation's health protection and health promotion response the federal government is inextricably involved. For purposes of this conference we should consider how best to access and benefit from the current federal resources and also ponder future federal roles and responsibilities. From a community perspective what has been the most helpful federal government role? The least helpful? At what stage in the "life cycle" of a program is the federal government most needed? If you were able to design the ideal role for the federal government, what would it be?

Your comments questions will stimulate our discussion of where we need to go and how.

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CDC Oral Health Resources
http://www.cdc.gov/OralHealth/

HRSA supported National Maternal and Child Oral Health Resource Center
http://www.mchoralhealth.org/

NIDCR Oral Health Information Clearinghouse
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http://drc.nidcr.nih.gov/

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