Conference Paper

Improving Oral Health for Individuals with Special Health Care Needs

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Abstract: *The purpose of this paper was to highlight information and issues raised in a keynote address for the American Academy of Pediatric Dentistry's Symposium on Lifetime Oral Health Care for Patients with Special Needs held in November, 2006. Topics include: (1) relevant statistics and definitions; (2) the prevalence and impact of common oral diseases in individuals with special health care needs (ISHCN); (3) an overview of oral health care delivery for ISHCN; (4) key delivery system and policy issues; and (5) a synopsis of major contextual initiatives related to ISHCN. In light of the Academy's primary interest in infants, children, and adolescents—including children with special health care needs—the major focus is on children. Significant oral health and oral health care issues for adults with special needs, however, generally parallel those for children and are of interest to the Academy, particularly as they relate to the transition from pediatric care to adult care, a critical period for extending the level of oral health and health trajectory established during childhood. (Pediatr Dent 2007;29:98-104)*

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Individuals with special health care needs (ISHCN) comprise a substantial and growing segment of the US population. Nearly 1-in-5 school-age children and nonelderly adults are considered to have special health care needs.[1] While the prevalence of special health care needs among seniors is higher than in younger individuals and increases with age, approximately 7 out of 10 ISHCN are children or nonelderly adults.[1] Among children and nonelderly adults, some 27 million have physical impairments and 10 million have some type of mental health problem.[1]

The broad categorical term "ISHCN" encompasses a wide variety of physical, developmental, mental, sensory, behavioral, cognitive, and emotional impairments that require medical management, health care interventions, and/or use of specialized services or programs.[1-3] Providing health care for individuals with special needs, by definition, necessitates a range of knowledge and accommodative measures that go beyond what is considered routine. The range of special knowledge, skills, and accommodations necessary to provide such services varies widely, however, depending on the nature and extent of each individual's condition. The basic oral health needs of most ISHCN can be met in traditional dental care settings by clinicians and support staff trained to adjust routine treatment approaches to accommodate individuals' special needs. Others, albeit a relatively small minority, require treatment by clinicians with more advanced training and special facilities (eg, outpatient sedation or treatment under general anesthesia) at least on an occasional basis.

Numerous policies and programs have been established to facilitate access to quality health services for ISHCN. Nevertheless, analyses of national data have determined that a greater percentage of ISHCN have unmet health care needs relative to the general population. Based on analyses of national survey data, Mayer and colleagues[4] concluded that a substantial minority of children with special health care needs (CSHCN) have unmet needs for both routine and specialty care, with unmet needs being greatest among those without insurance or in poor or near-poor families. Of particular relevance to the topic of this publication, dental care has been found to be the most common category of unmet health care services for CSHCN.[5]

The purpose of this paper was to highlight information and issues raised in a keynote address for the American Academy of Pediatric Dentistry's (AAPD) Symposium on Lifetime Oral Health Care for Patients with Special Needs held in November, 2006. Topics include:

1. relevant statistics and definitions;
2. the prevalence and impact of common oral diseases in ISHCN;
3. an overview of oral health care delivery for ISHCN;
4. key delivery system and policy issues; and
5. a synopsis of major contextual initiatives related to ISHCN.

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In light of the AAPD's primary interest in infants, children, and adolescents—including CSHCN—the major focus is on children. Significant oral health and oral health care issues for adults with special needs, however, generally parallel those for children and are of interest to the AAPD, particularly as they relate to the transition from pediatric care to adult care. This transition is a critical period for extending the level of oral health and health trajectory established during childhood throughout life.

Relevant statistics and definitions

Expenditures. ISHCN use more health services, have higher health care costs, and incur greater out-of-pocket health care expenditures compared to others in the population. Annual total health care expenditures for CSHCN in 2000 averaged $2,335 vs $652 for other children. As is the case in the general population, however, the distribution of health care costs in CSHCN is highly skewed, with 10% of individuals accounting for 61% of all health care expenditures.[6] Similarly, CSHCN have greater average annual out-of-pocket expenses for health care compared to other children ($343 vs $171 in 2000), with 10% of families accounting for 54% of out-of-pocket expenditures of CSHCN.[6] Median total and out-of-pocket health care expenditures for CSHCN in 2000 were $558 and $100, respectively.[6]

Significant portions of the costs of care for CSHCN are covered by public programs such as Medicaid, State Children's Health Insurance Program (SCHIP), and state Title V or Maternal and Child Health (MCH) programs.[6] Medicaid coverage also is an important source of health care payment for many adults with disabilities. Medicaid coverage for adults with special needs, however, is subject to each individual's financial circumstances and state discretion, and often is less comprehensive in terms of scope and depth of coverage (especially regarding dental benefits).

Definitions. Having clear definitions to guide program planning and the identification of individuals with special needs who qualify for various programs is an important consideration, one which has taken on added importance of late as the result of changes in program financing and expansion of managed care arrangements. For children, the following definition of CSHCN put forth by the federal Maternal and Child Health Bureau serves as a general guide for state and federal programs for children:

> 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.[2]

Some 9.5 to 12.5 million children and adolescents in the United States fit this definition, which is used by all 50 states for planning and policy purposes.[7]

Another definition developed by the National Center for Health Statistics applies to both children and adults, and classifies someone as having a disability if he or she has any of the following:

1. a specific physical, functional, mental or emotional disability or limiting condition;
2. significant limitations in performing daily self-maintenance activities;
3. need for the use of special equipment or devices such as a wheelchair or breathing aid;
4. limitation in a major or other life activity because of physical, mental, or emotional problems;
5. income or insurance based on disability; and
6. other indicators of disability, such as poor overall health status, use of specialized programs or services, or other behavioral indicators of disability or developmental delay.[8]

Major types of conditions encompassed by these definitions are listed in Table 1. The list of conditions is not exhaustive and is included merely for illustrative purposes.

Table 1. EXAMPLES OF CONDITIONS GENERALLY INCLUDED IN DEFINITIONS OF SPECIAL NEEDS

- Anxiety/ADHD/depression
- Asthma
- Autism
- Cognitive disorders (eg, mental retardation, earning disorders)
- Craniofacial disorders (eg, cleft lip, cleft palate)
- Developmental disorders (eg, cerebral palsy, spina bifida)
- Diabetes
- Emotional disturbances
- Hemophilia
- HIV infection
- Musculoskeletal disorder
- Syndromes (eg, Down syndrome, ectodermal dysplasia, fetal alcohol syndrome, neurofibromatosis, Treacher-Collins syndrome)
- Vision, speech, and hearing impairments

Impact

The impact of special health care needs on children and their families is profound. Compared to other children, children with special health care needs (CSHCN):

1. are 3 times more likely to be ill and miss school;
2. have over 3 times as many hospitalizations and 7 times as many hospital days;
3. have more than twice as many physician visits and almost 7 times as many nonphysician health care visits; and
4. take 5 times as many prescribed medications.[9,10]

Nearly 60% of CSHCN experience functional impairment as a result of these conditions and associated health care needs, with 37% of parents reporting that their children sometimes have impairments, and 23% reporting that functional impairments occur usually or always or a great deal of the time.[9] CSHCN from low-income households are 1.5 to 2.5 times more likely to experience a functional impairment compared to more affluent children.[9]

Need and unmet need

Caregivers of CSHCN report that dental services are the second-most needed health care service for their children—78% report a need for dental services vs 88% for prescription medications.[9] The fact that the reported need for dental care (and routine preventive health services) is not universal—ie, not 100%—is a common finding in surveys of parents and caregivers, and represents a cause for concern for child health professionals and policy makers.[4,11]

Dental care is reported to be the most common unmet health care need in CSHCN, with 8% of parents or caregivers who participated in recent national surveys reporting that their children needed dental care that they were unable to obtain.[4,9] CSHCN from low-income families are 3_ to 4 times more likely to have unmet health care needs than more affluent children.[4,9] Unlike unmet needs for medical care, prescription drugs, vision care, and mental health services, however, an unmet need for dental care is reported to not differ by race and ethnicity.[4]

Insurance coverage

Because health care costs for CSHCN are substantially greater than for other children, insurance coverage is an important factor in obtaining health care services for families with CSHCN. Recent surveys indicate that 65% of children with disabilities or other special health care needs are covered by private or employer-sponsored health insurance.[9] Medicaid, SCHIP, and other public programs are reported to be the next most common form of coverage for CSHCN (22%), while 8% have some combination of private and public coverage.[9] Despite the fact that fewer children are covered by Medicaid than by private insurance, Medicaid pays a disproportionately high percentage of total heath care costs for CSHCN due to a number of factors including its broader scope of coverage and enrollment of children who have more extensive health care needs.[6]

Medicaid coverage is likely to take on added significance as a result of a recent national policy shift instituted via the federal Deficit Reduction Act (DRA) of 2005. The DRA creates a new, optional Medicaid eligibility group (effective January 1, 2007) that consists of children with disabilities under age 19 who meet the Supplemental Security Income (SSI) program rules for severity of disability, but not the income rules. Under this option, states may extend Medicaid eligibility to such children in families with income up to 300% of the federal poverty level (FPL)—currently set at $58,500 for a family of four. States also may extend coverage to families above 300% of the FPL without federal matching funds.[12]

The range of CSHCN who are reported in national surveys to be uninsured varies between 5% to 11%.[1,9] As with many reports on "the uninsured," however, these figures generally refer to those who lack coverage for medical benefits (often referred to as "health coverage") and do not reflect those who lack dental benefits (generally a significantly larger segment of the population). A recent national survey found that 18% of CSHCN were reported as not having dental coverage.[11] The significance of CSHCN being uninsured stems from reports that nearly half of "uninsured" CSHCN do not receive needed health care services, with 29% failing to obtain needed dental care and 14% failing to obtain needed mental health services.[9]

Prevalence and impact of oral diseases and conditions.

The Surgeon General's Report on Oral Health pointed out that no national studies have been conducted to determine the prevalence of oral diseases and craniofacial abnormalities among various populations with disabilities.[13] Sources of information on the oral health of CSHCN and their utilization of dental services generally are limited to:

1. studies of individuals with specific, relatively common conditions (eg, mental retardation);
2. aggregated findings for diverse groups of individuals encompassed by the definition of CSHCN; or
3. surveys that rely on parental reports of their children's conditions.

Consequently, the knowledge base concerning the oral health status of ISHCN is rather incomplete and fragmented.

Findings from a recent review of literature concerning the most common categories of oral diseases and conditions[14] indicate the following regarding individuals with disabilities or other special health care needs:

1. The majority of evidence suggests that individuals with disabilities have more untreated caries than those in the general population.

2. Individuals with mental retardation are likely to have a higher prevalence of gingivitis and other periodontal diseases compared with the general population.
3. While the true prevalence of malocclusions in CSHCN is unknown, these children often are prone to develop malocclusions as a result of abnormal developmental processes and muscle function.
4. Problems related to poor oral hygiene and dental/orofacial trauma also are generally considered to be more prevalent in ISHCN than in the general population.
5. Nearly two thirds of community-based residential facilities report that inadequate access to dental care is a significant issue for their residents.

A recent national telephone survey of parents and caregivers[11] found that 65% of CSHCN were reported to be in excellent or very good oral health. Nearly 23% were reported to have good oral health, and 1-in-8 was reported to have fair or poor oral health. The reported prevalence of fair or poor oral health was higher for children with the following conditions: (1) speech disorders (23%); (2) behavior disorders (21%); (3) intellectual disabilities (20%); (4) developmental/physical disabilities (19%); (5) autism (19%); (6) hearing/vision impairments (19%); (7) musculoskeletal problems (18%); (8) depression or anxiety (17%); and (9) attention deficit disorder (12%).[11] These results are likely to under-represent the true extent of dental problems in CSHCN because of the limitations of parents' assessments of their children's oral health.[15]

The clinical consequences of dental diseases and orofacial developmental disorders on oral health status have been widely documented. Less appreciated—at least prior to the recent publication of the US Surgeon General's Report on Oral Health[13]—are the associated consequences of dental diseases and orofacial developmental disorders on mastication, nutrition, speech, appearance, learning, and general well-being. *The Surgeon General's Report* and other recent reports in the literature also have stimulated considerable interest in the potential relationships among oral/dental conditions and other medical comorbidities (eg, cardiovascular disease, cerebrovascular ischemia, stroke, respiratory infections, diabetes, adverse pregnancy outcomes).[13,16] Collectively, these findings have brought renewed attention to the importance of linkages between oral health and general health and well-being, especially for those shown to be at significant risk for poorer oral health, including ISHCN.

Oral health care delivery for ISHCN

Deinstitutionalization and increasing life expectancy for ISHCN are creating increasing pressures on an oral health care delivery system that has shown limited ability to adequately meet their needs heretofore. Data on dentists' willingness to provide care for ISHCN are limited. Available data suggest, however, that dentists often are unwilling to:

1. accept patients with disabilities into their practices;
2. publicly announce that they are willing to treat individuals with disabilities; or
3. provide care to individuals with disabilities on a very limited basis.[17-20]

For example, a survey by Casamassimo et al20 found that only 10% of 1,251 general dentists reported that they treated CSHCN often or very often, while 70% reported that they rarely or never treated CSHCN. Pediatric dentists appear to be much more likely to provide dental care for CSHCN, as evidenced by a survey of AAPD members which reported that 95% routinely treat CSHCN.[21] The relatively small number and distribution of pediatric dentists, however, means that broader involvement by general dentists is needed to address access to care issues for ISHCN.

Barriers. Predominant barriers to the delivery of oral health care for ISHCN cited in the literature generally relate to 3 categories:

1. factors concerning special needs patients' behavior, disability level, and extent of oral disease/treatment needs;
2. training for dentists and office staff in managing ISHCN; and
3. financing and reimbursement for direct and adjunctive services required to provide treatment for ISHCN.[17,19,20,22]

Surveys of parents and caregivers of CSHCN generally identify cost, insurance coverage, and availability of appointments as the most common barriers to obtaining dental care. For example, respondents who participated in the 2003 National Survey of Children's Health indicated that the most common reasons why their CSHCN did not receive needed dental care were:

1. lack of insurance (30%);
2. high cost of dental care (28%);
3. health plan problems (14%);
4. inability to get an appointment or inconvenient appointment times (12%); and
5. having insurance that was not accepted by the dentist (10%).[11]

Results of other analyses indicate that unmet dental needs affect more children than any other unmet health care need—more than 750,000 children by recent estimates.[23]

Recommendations. Within the dental literature, most recommendations for addressing current delivery system shortcomings in providing oral health care to ISHCN focus on workforce or financing issues, such as:

1. increasing the size of the dental workforce;
2. providing additional training for dentists and other members of the dental care delivery team;

3. improving reimbursement for dental services for ISHCN.[19,20,22]

Others point to the need for "special programs" or alternative care delivery arrangements (eg, hospital, university or mobile dental programs) to complement the care provided through private practices as a strategy to address access issues for ISHCN.[16]

At another level, the federal Maternal and Child Health Bureau and, by extension, state MCH programs have devoted considerable resources toward the development of community-based systems for CSHCN that emphasize:

1. partnering with families to promote shared decision-making and greater satisfaction with services;
2. coordinated, ongoing, comprehensive care within a "medical home";
3. adequate private and/or public insurance to pay for needed services;
4. early and continuous screening to identify special health care needs;
5. organizing services so that families can use them easily; and
6. services that facilitate the transition from youth to adult life, including adult health care, work, and independence.[24]

The "medical home" is a major feature of these systems and reflects a recognition that care for individuals with special needs is best served by having a central professional point of contact for ongoing primary health care services and coordination of care when care is delivered by a multitude of clinicians and support service providers. The "dental home" concept championed by the AAPD and embraced by other dental professional organizations closely parallels the essential elements of the medical home as they relate to the provision of dental care.

Linkages between patients' medical homes and dental homes, however, often are not as formally established as linkages among medical care providers, frequently resulting in inattention to dental services for CSHCN.[23] Therefore, efforts to establish better linkages between medical homes and dental homes appears to be an important area of endeavor within the context of MCH efforts to develop community-based systems to adequately meet the full range of health services for ISHCN.

Policy issues. An in-depth discussion of policy issues related to oral health care delivery for ISHCN is

Table 2. MAJOR POLICY ISSUES CONCERNING INDIVIDUALS WITH SPECIAL NEEDS

BENEFITS/COVERAGE
• Medicaid, Medicare, SCHIP, Commercial coverage
• Adequate dental benefits for children and adults
• Adequate support services
• Access to specialty care when necessary
DEVELOPMENTAL DISORDERS (EG, CEREBRAL PALSY, SPINA BIFIDA)
• Adequate resources for benefits/coverage/plans
• Reimbursement for additional time, training, equipment, and supplies required to provide services for ISHCN
• Adequate resources for programs/facilities to provide advanced special needs care
HIV INFECTION
• Clinical guidelines for ISHCN
• Program policies that specifically address ISHCN
SURVEILLANCE AND RESEARCH
• Epidemiological surveys
• Translational research focused on improving health care and outcomes for ISHCN
SYSTEMS DEVELOPMENT
• Care coordination
• Dental home—medical home linkages
• Specialized facilities (centers) for individuals with complex treatment needs
TRAINING
• Dentists and dental hygienists
• Physicians and other primary care providers
• Allied health care professionals
• Home health care providers
• Lay health workers
• Families and caregivers
WORKFORCE
• Adequate number and distribution of providers with necessary special needs skills

beyond the scope of this paper. Several key policy issues related to oral health care for ISHCN, however, are outlined in Table 2. The overarching goal for policy development concerning ISHCN is ensuring that adequate resources and systems exist to provide quality care for the diverse groups of ISHCN.

Contextual initiatives

In 2005, the US Surgeon General launched the Call to Action to Improve the Health and Wellness of Persons with Disabilities.[25] In addition to providing definitions, detailed facts about disabilities, and common challenges and resources for persons with disabilities, the Call to Action highlights a number of important themes, including:

1. Many Americans experience disabilities first hand.
2. Anyone can have a disability.
3. Much can be done to improve the health and wellness of persons with disabilities.
4. People with disabilities can lead long, healthy lives.
5. Choices affect a person's ability to lead a healthy lifestyle.
6. Health professionals are responsible for treating the whole person, not just the disability.

The Surgeon General also held a conference and issued a report in December, 2001 called Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation.[26] These high-level federal activities acknowledged the difficulties faced by individuals with mental retardation and developmental disabilities and pointed to a critical failure to ensure access to quality medical and dental care for this vulnerable segment of the population. One outgrowth of this initiative was the founding of the American Academy of Developmental Medicine and Dentistry (AADMD). The AADMD was established in May 2002 as a national, professional, 501(c)(3) nonprofit organization of physicians and dentists with expertise and interest in the care of patients with mental retardation and developmental disabilities. Central to the AAPD's vision is the full partnership of dentistry and medicine in addressing the short- and long-term health needs of this population.[19]

These 2 federal initiatives, along with the Surgeon General's Report on Oral Health in America and the Call to Action to Promote Oral Health,[27] constitute the major environmental context for addressing the oral health needs of ISHCN. Responses to these initiatives and ensuing actions on the part of the government, professional organizations, business community, advocacy groups, and the public will largely determine the extent of improvements in oral health for ISHCN in the near- and long-term.

Conclusions

An oft-cited quote attributed to Hubert H. Humphrey[28] seems particularly apropos to the central focus of this paper and the AAPD's Symposium on Lifetime Oral Health Care for Patients with Special Needs:

> "It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped."

This statement would appear to apply equally to the health professions. And the inclusion and stature of the dental profession and its various components among the health professions is likely to be judged by the extent to which they respond to these challenges.

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