

GUEST EDITORIAL

The transition of children with disabilities to adulthood What about dental care?

Our system of preparing and maintaining our abilities to provide oral health services for an increasingly diverse population must be brought up to date to meet the challenges posed by the treatment of young adults with disabilities.

In 2008, more than 1.2 million people between 16 and 20 years of age (5.6 percent of late-age teenagers in the United States) reported they had one or more disabilities. More than 850,000 had cognitive disabilities, more than 418,000 had independent living difficulties, 213,000 had visual disabilities and almost 200,000 had ambulatory disabilities.¹

Each year, 4.2 million 20-year-old U.S. residents (including about 235,000 people with disabilities) reach their 21-year transitional age.² At that point, they lose their eligibility (depending on family income and related factors) for Medicaid dental care under the Early and Periodic Screening, Diagnostics and Treatment federal-state program—a program that mandates comprehensive and preventive care for qualified people younger than 21 years but designates adult dental benefits as “optional.”³

The State Children’s Health Insurance Program (SCHIP) was enacted in 1997 to provide a capped amount of federal matching funds to states for coverage of children and some parents with incomes too high to qualify for Medicaid but for whom private health insurance was either unavailable or unaffordable. Covering roughly four million children, SCHIP has played an important role in reducing the number of uninsured children in this country.⁴

Although dentistry for children was elective under the SCHIP legislation, most state programs included dental services. In 2007, the reenactment of SCHIP as the Children’s Health Insurance Program (CHIP)—with the removal of the word “state” to emphasize the “national” concept of the legislation—mandated the inclusion of dental services for all children as old as 19 years who are eligible in a particular state. The reality is that the Medicaid/CHIP programs provide a critical funding source for needed medical and dental services for youngsters with disabilities.^{5,6} The new 2010 health reform legislation expands Medicaid to a national floor of 133 percent of poverty (\$14,404) for a person or about \$29,326 for a family of four in 2009, but it does not mandate Medicaid dental services for adults.⁷

The 2006 National Survey of Children with Special Health Care Needs reported that more than 81 percent of children with special

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health care needs (CSHCN) had needed preventive dental care and 24 percent had needed other dental care within the preceding 12 months. Preventive dental care was second only to prescription medication in the frequency of need. Overall, almost 580,000 CSHCN, or 8.9 percent of CSHCN, who needed dental care were unable to obtain it (including 7.4 percent for preventive care and 10.3 percent for other dental needs). According to Lewis,⁸ “dental care was the most common unmet need of CSHCN ... a [statistically] significantly higher proportion of CSHCN relative to children without special health care needs ...” In particular, 10.6 percent of teenagers aged 13 to 17 years with special health care needs—those approaching the end of their Medicaid/CHIP eligibility years—had unmet dental care needs.⁸

The era of institutionalization of most youngsters and adults with special needs has been replaced with mainstreaming, establishment of community-oriented group residential settings and family support locations—all of which has led to increased dependence on private community practitioners to provide dental and medical services. In an effort to prepare the next generation of dentists to provide services for the “new” residents of our communities, the Commission on Dental Accreditation adopted the standard that “Graduates [of dental schools and schools of dental hygiene] must be competent in assessing the treatment needs of patients with special needs.”⁹

Whether because of the financial and bureaucratic limitations of the Medicaid/CHIP programs or other factors, the reality is

that general and specialist practitioners are providing only limited oral health services for children and adults with disabilities and a wide range of special needs. The facts are these:

- many children are aging out of programs that provide support for oral health care into a virtual void of financial assistance in most states;
- only 10 percent of general dentists report that they treat children with cerebral palsy, intellectual disabilities or medically compromising conditions often or very often;
- 70 percent report that they rarely or never treat children with cerebral palsy in their practices.¹⁰

The unresolved issue is the reality that adult Medicaid dental care in many states is limited to relief of pain and infection—even for adults with disabilities. In essence, youngsters with special needs are aging out of dental care. It is essential to challenge a system that overlooks the most vulnerable residents in our communities. In the interim, the need is to update and better prepare current practitioners for the increasing complexities of services for people with special needs, many of whom are members of families currently being treated in many dental practices. A review of continuing education offerings at larger dental meetings revealed limited attention to the care of people with special needs.

The profession that we entered so many years ago seemed far simpler than the one in which we function today, one that includes the needs of young adults with disabilities who reside in our communities. Our system of preparing and maintaining our abilities to provide oral health services for an in-

creasingly diverse population must be brought up to date to meet these challenges. A continuing education menu related to the care of people with disabilities to meet relicensure requirements is one approach that should be explored. ■

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