

## Children With Mental Retardation/Developmental Disabilities: Do Physicians Ever Consider Needed Dental Care?

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In the late 1960s, there were more than a quarter of a million individuals with mental retardation/developmental disabilities in state institutions. During the next 30 years, the number of residents decreased by more than 75% (Anderson, Lakin, Mangano, & Prouty, 1998). Changing social policies, favorable legislation for people with disabilities, and class-action legal decisions, which delineated the rights of individuals with mental retardation, have led to deinstitutionalization (i.e., mainstreaming, establishment of community-oriented group residences and enhanced personal family residential settings) and closure of many state-run large facilities.

Many of the community residential facilities are too small in size to provide services within the residence. As a consequence, the monitoring of health care can be difficult when the delivery of service and health records are disseminated among multiple providers and locations. Thus, although most infants, children, and adolescents with mental retardation live with their natural or foster parents, pediatric and general practitioners may need to interact with a large and varied group of health providers. The success of community-based health programs, therefore, depends on:

- The capacity to organize and maintain the services and health records of these “new” community residents and increasing numbers of youngsters with mental retardation/developmental disabilities in existing community families.
- The ability of pediatric and general practitioners, who provide consultation and medical “gatekeeping” services for the population with mental retardation/developmental disabilities, to recognize and identify the wider range of needed health services—including preventive and restorative dental care.
- The availability of private practitioners who are (a) convenient and accessible to the deinstitutionalized individuals and (b) are trained and willing to provide the needed care.

The complex never-ending needs of children

with mental retardation/developmental disabilities and their families may at times seem to overwhelm the best of intentions and efforts by pediatricians and family practitioners. Given these realities, is dental care “really that important”? Maybe, more than we think. As Kozol (1991) noted:

Children get used to feeling constant pain . . . (from) bleeding gums, impacted teeth and rotting teeth. . . They go to sleep with it. They go to school with it. . . The gradual attrition of accepted pain erodes their energy and aspiration. (pp. 20–21)

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### Dental Care Needs

No nationwide studies have been conducted to determine the prevalence of dental diseases among the various populations with disabilities. Numerous local and regional reports, however, provide a general appreciation of the needs. The population with disabilities has significantly higher rates of poor oral hygiene, gingivitis, and periodontitis than do members of the general population. There is a wide range of caries (tooth decay) rates among people with disabilities; but, overall, their rate is significantly higher than that of the general population. Much of the variation stems from where the people reside (Acs, Shulman, Ng, & Cussid, 1999; Beck & Hunt, 1985; Waldman, Perlman, & Swerdloff, 1998; White, Caplan, & Weintraub, 1995).

As with general medical care, when youngsters (and adults) were residents of state institutions, they were to some extent assured of dental services from state employees. Although many (most?) institutions were underfunded and understaffed in direct care and professional services, many large state institutions had a dental clinic with general dental practitioners as well as specialist consultants. Deinstitutionalization, with resulting community group homes and family residences, has resulted in a breakdown in the continuity of services—especially dental services. Thus, deinstitutionalization has (a) added great numbers of individuals with spe-

cial health needs to the vast majority of children and adults with mental retardation/developmental disabilities who always have lived in our communities and (b) complicated further the efforts to secure needed dental services.

As a result, parents/guardians, community resident managers, and other individuals responsible for the care of children with mental retardation/developmental disabilities increasingly must assume the responsibility of obtaining the needed dental care from community practitioners, many of whom are reluctant to provide essential services. This reluctance often results from a combination of limited training, experience, and interest as well as unrealistic financial reimbursement—most often provided through the Byzantine labyrinth of the Medicaid program.

Added to the usual range of dental care needs, children with mental retardation/developmental disabilities often present with numerous and/or advanced cases of baby-bottle tooth decay/early childhood caries, prescription-medication-induced dental decay, altered salivary flow and tooth decay, “placating” tooth decay, malocclusions, fractured and nonvital teeth, soft tissue complications, and bruxism

*Baby-bottle tooth decay/Early childhood caries.* A child’s bedtime or naptime use of a bottle containing juice, milk, formula or any liquid sweetened with fermentable carbohydrates can lead to rampant decay. Its first clinical sign begins insidiously as a whitening/decalcification of the maxillary primary incisors. If the child remains on the nighttime bottle, decay can progress very rapidly. It is important to note that demand breast-feeding can lead to similar but usually not as severe conditions of tooth decay.

This disease pattern is important because extensive treatment is required before the child is old enough to cooperate for restorative dental care, necessitating some form of restraint or possible sedation or general anesthesia in an ambulatory surgery or hospital setting at a high cost of care. Major loss of tooth structure, which could lead to an eventual extraction, can affect developing speech patterns and food consumption and, if not monitored, may result in the loss of space maintenance for the permanent dentition. This may then cause significant malocclusion problems, abnormal jaw development, marked alterations in mastication, poor esthetics, and a negative self-image.

Studies indicate that prior to oral rehabilitation, young children with baby-bottle tooth decay demonstrate significantly less weight gain than do their typical counterparts. Comprehensive dental rehabili-

tation results in catch-up growth (Acs et al., 1999). Early counseling and establishment of proper feeding practices, in particular discontinuance of the sleep-time bottle, is important (Infant Oral, 2000).

*Prescription-medication-induced dental decay.* “A little bit of sugar may help the medicine go down,” but antibiotics, pain, seizure control, and antihistamine medication, laced with sugar to mask the taste, can prove to be an ideal medium for bacterial growth and dental decay (Feigal & Jensen, 1982).

*Altered salivary flow and tooth decay.* Psychotropic medication used to help in the care of children with mental retardation/developmental disabilities can decrease salivary flow, resulting in xerostomia (dry-mouth), salivary glands with retrograde infections, and possible stone formation, as well as increased rates of dental decay,

*“Placating” tooth decay.* Fruit roll-ups, candy bars (anything from “Gummy Worms” to “Skittles” to “Now and Later,” and, yes, pediatrician-dispensed lollipops) may meet the immediate need to calm and soothe a child, but combined with numerous other contributing factors, they may dramatically increase decay rates. In addition, frequent snacking of heavily sugar-coated cereals is also a potential source of extensive tooth decay.

*Malocclusions.* Functional and esthetic malocclusions may result from (a) unfavorable habit development (including finger-sucking, mouth-breathing, tongue-thrusting); (b) absence of a diet that includes rough and coarse food requiring thorough chewing; (c) increased levels of unrestored caries; (d) overretained primary teeth; and (e) the loss of teeth, tooth structure, and lack of space maintenance. Malocclusions may develop as a consequence of pre- and postnatal trauma, hereditary factors, or poor muscle development, and severe esthetic malocclusions can compromise already difficult social relationships and potential employment opportunities.

Although it may seem “convenient” to approach the situation with the view that behavioral management complications preclude interceptive orthodontic treatment, interceptive and rehabilitate services are, in many cases, possible.

*Fractured and nonvital teeth.* Such problems are the result of trauma and advanced dental decay. Broken and/or blackened teeth are indicators of potential infection and should be monitored and, if necessary, restored.

*Soft tissue complications.* Seizure medication (e.g., Dilantin) can cause hypertrophy or over-

growth of the gingival tissue. This can lead to difficulties in mastication and advanced periodontal problems. It also is a causative factor in delayed exfoliation of primary teeth and delayed eruption of permanent teeth.

**Bruxism.** This condition is the grinding of teeth and usually is reported to occur while a child is asleep (*bruxomania* is the grinding of teeth when the child is awake). Many children engage in some form of bruxism that results in moderate wear of the dentition. However, continued wearing away of teeth can endanger the vitality of the teeth. Children with cerebral palsy and/or moderate to severe mental retardation often grind their teeth with greater frequency and intensity (Parker, 1999). Central nervous system disturbances have been postulated to precipitate bruxism, but there is no agreement as to the specific structure or the particular mechanism (Parker, 1999).

As with all forms of medical and dental services, early intervention is preferable to extensive services at some later date. It is particularly imperative for children with mental retardation/developmental disabilities. (School nurses continually emphasize that the most common pain problem they see in youngsters is related to dental needs.)

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## Commentary

### Care

Infant oral health care begins ideally with prenatal health counseling for parents. An initial oral evaluation visit should occur within six months of the eruption of the first primary tooth and no later than twelve months of age. (Infant Oral Health Care, 2000, p. 77)

It is critical for the pediatrician to evaluate fully the oral cavity and dental structures as a component of the total care of the child. Yet, three quarters of a random national sample of pediatricians who had completed their residency training in 1978 or later (in the early 1990s) reported “insufficient participatory experience and learning opportunities during pediatric residency” (Wender, Bijur, & Boyce, 1991, p. 876) in the field of dentistry. Despite improvements in various pediatric residency training experiences from earlier periods, respondents to both this study and the previous 1978 report by the American Academy of Pediatrics Task Force on Pediatric Education (except for experience in office management), most often designated dentistry as the field with “insufficient” experience (Wender et al., 1992).

Despite the fact that residency programs have not addressed this deficiency, the oral health needs of children, especially youngsters with mental retardation and other developmental disabilities, require a coordinated relationship between pediatricians and pediatric dental practitioners. In most cases, the pediatrician serves as the “gatekeeper” for early oral health care evaluation and needed preventive and rehabilitative services. The urgency is for the pediatrician to recognize the need to help youngsters develop a “dental home” for the oral health needs, analogous to the “medical home” advocated by the American Academy of Pediatrics. Before this is possible, however, the pediatrician’s recognition of a youngster’s oral health is essential. To this end, they need to consider the following questions:

- Is oral hygiene adequate?
- Is there clinically visible decay?
- Is there overgrowth of the soft tissue?
- Do frenums interfere with tongue and lip movements?
- Are there abnormal tissue areas on the tongue, lips, cheeks, and gums?
- Are orofacial growth and development within in normal parameters?

In addition, programs by pediatricians to prevent dental diseases should be considered. For example, in North Carolina, when children receive routine checkups in offices of pediatricians, in an effort to prevent tooth decay, nurses are applying fluoride varnishes on the teeth of children in at-risk populations.

### Realities

Factors contributing to breakdown in the continuity of dental services (lack of adequate trained and willing community-based dental providers, inadequate reimbursement, particularly through the Medicaid program) and “managed care attitudes” are quite similar to the problems faced by parents seeking pediatric medical services for their children with mental retardation/developmental disabilities. As Pear (2000) noted, “H.M.O.’s [sic] often refuse to pay for surgery on children to correct cleft lip and cleft palate, contending that such procedures are a form of cosmetic surgery and are therefore not covered by the insurance policy” (p. A20).

The issue is one of recognition and public relations by the medical and dental professions as well as the general public. The “out-of-sight, out-of-mind” at-

titude worked well prior to deinstitutionalization and the mandate of dentistry within the Early Periodic Screening, Diagnosis and Treatment program of Medicaid. Community residences, however, mainstreaming, and the Americans With Disabilities Act have changed the proverbial “playing field.”

One could argue that raising pediatric practitioner awareness of oral health needs without expanding resources for care will not necessarily be helpful and may only prove frustrating to parents and providers, but professional and community reaction can have a positive impact. For example, after a significant lobbying effort, a recent amendment to New York State Health Insurance Regulations now requires health insurance policies written in New York to cover congenital disease or anomalies that affect oral health, for example, ectodermal dysplasias and cleft lip and palate (*Insurance amendment*, 2000).

Yes, efforts at capitation, “carve-outs,” and the like could be effective steps in helping to meet the dental care of youngsters with special needs. However, these efforts require (a) sufficient awareness of the significance of the problem and (b) a willingness of third parties (both insurance companies and government agencies). For example, in Oregon, “The reimbursement (rates) for people with disabilities is 10-times the base rate, serving as an incentive to attract practitioners” (Dougherty, Romer, & Birenbaum, 1997, p. 14).

In the meantime, pediatric residency programs must respond to their own surveys, which indicate a paucity of experience in dealing with dental needs (and by extension) the special dental needs of youngsters with mental retardation/developmental disabilities. Finally, an essential step would be for individual practitioners to establish a working relationship between pediatric and family physicians and pediatric dentists.

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