

The American Academy of Developmental Medicine and Dentistry: Eliminating Health Disparities for Individuals with Mental Retardation and Other Developmental Disabilities

Sanford J. Fenton, D.D.S., M.D.S.; Henry Hood, D.D.S.; Matthew Holder, M.D., M.B.A.; Philip B. May, Jr., M.D.; Wendy E. Mouradian, M.D., M.S.

Abstract: Recent reports by Special Olympics International and the U.S. Surgeon General have revealed significant disparities and unmet health needs encountered by persons with mental retardation and other developmental disabilities (MR/DD). Factors contributing to these disparities include deinstitutionalization, increased survival of individuals with MR/DD, lack of appropriately trained providers, and inadequate financing of dental services. To address these problems, a group of academically oriented dentists and physicians formed the American Academy of Developmental Medicine and Dentistry (AADMD). The mission of the AADMD is to improve the quality of health services provided to persons with MR/DD by improving dental and medical school-based training of dentists and enhancing clinically relevant research. A central theme of the AADMD is full collaboration between physicians and dentists in meeting its goals. The National Action Strategy developed by the AADMD focuses on creating a series of university-based Developmental Medicine and Dentistry Programs (UDMDPs) in medical and dental schools, which collaborate in service, teaching, and research with community-based primary care clinics, community hospitals, intermediate care facilities, and other private service delivery systems such as the Special Olympics Healthy Athletes Program that serve these patients. Oral-systemic interactions will receive special emphasis by the training and research programs.

Dr. Fenton is Professor and Chair, Department of Pediatric Dentistry and Community Oral Health, University of Tennessee Health Science Center; Dr. Hood, now CEO of the Chyron Group and Policy Director, American Academy of Developmental Medicine and Dentistry, was formerly Program Director, Developmental Disabilities Dentistry Fellowship, University of Louisville School of Dentistry; Dr. Holder is Executive Director, American Academy of Developmental Medicine and Dentistry; Dr. May is President, American Academy of Developmental Medicine and Dentistry and Director, Developmental Medicine Program, Department of Medicine, University of Medicine and Dentistry of New Jersey/Robert Wood Johnson Medical School; and Dr. Mouradian is Associate Clinical Professor of Pediatrics, Pediatric Dentistry and Health Services (Public Health), University of Washington. Direct correspondence and requests for reprints to Dr. Sanford J. Fenton, Department of Pediatric Dentistry and Community Oral Health, University of Tennessee Health Science Center, College of Dentistry, 875 Union Avenue, Memphis, TN 38163; 901-448-6206 phone; 901-448-6249 fax; sfenton@utmem.edu. Dr. Mouradian's work at the University of Washington is supported by funding from Health Resources and Services Administration's Bureau of Health Professions (cooperative agreement #8 U7 HP 00026-01), the Maternal and Child Health Bureau (training grant #1 T17 MC 00020-01), and the Comprehensive Center for Oral Health Research through its grant from the National Institute of Dental and Craniofacial Research (#P60 DE13061).

Key words: oral health disparities, mental retardation, developmental disabilities, medical-dental collaboration

Submitted for publication 9/25/03; accepted 11/13/03

Individuals with mental retardation and developmental disabilities (MR/DD) and their families encounter difficulties accessing quality medical and dental care. In December 2001, a U.S. Surgeon General's conference and report, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*,¹ acknowledged these difficulties and pointed to a critical failure to ensure access to quality medical and dental care for this vulnerable population. One of the key recommendations of the *Closing the Gap* report is to improve the train-

ing of health care providers in the care of adults and children with mental retardation and developmental disabilities.

Prompted by this federal initiative, the American Academy of Developmental Medicine and Dentistry (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 academy's vision is the full partnership of dentistry

and medicine in addressing the short- and long-term health needs of this population. In particular, the academy is stimulating interest in medical and dental schools to address training gaps and to identify important areas for future research related to the needs of this population. This article articulates the need for new training models and describes the University-Based Developmental Medicine and Dentistry Programs (UDMDPs) being implemented in two academic institutions.

These UDMDPs are programs that provide training in the new academic fields of Developmental Medicine and Developmental Dentistry. Developmental Medicine and Developmental Dentistry can be defined as the expertise and competencies required for medical and dental evaluation and treatment of those health conditions frequently encountered in adults with Childhood Onset Brain Dysfunction. Childhood Onset Brain Dysfunction, or C.O.B.D., refers to brain dysfunction of genetic or acquired etiology that manifests clinically before the age of twenty-one years. Adult patients with Childhood Onset Brain Dysfunction may be identified by the following “developmental disability” diagnostic labels: mental retardation, cerebral palsy, epilepsy, and/or autism. We prefer the term C.O.B.D. because of the variation in the definition of developmental disability from state to state (for the purposes of qualifying for public benefits). However, because “developmental disability” has been used in previous studies and reports, we retain its use in this article.

Background

The current push for training in developmental medicine and developmental dentistry is the result of three interacting factors: the trend toward deinstitutionalization of individuals with mental retardation and developmental disabilities (MR/DD); the increasing life span of this population and the resultant rise in health care access problems; and scientific evidence for the importance of oral-systemic health interactions. The current national focus on health disparities^{2,3} and the long-standing efforts of advocacy groups are adding momentum to this important agenda.

Deinstitutionalization

Since the 1960s, individuals with MR/DD have been moved out of institutions and into community

settings, in keeping with the principles of “mainstreaming” and delivery of services in the “least restrictive setting.”⁴ Prior to the 1960s, most of the adult population with MR/DD lived in and received health care in institutional settings. These institutions had at least a modicum of on-site medical and dental staff to treat patients, so the average community clinician saw few patients with developmental disabilities over the course of his or her career. As a result, few medical and dental schools concerned themselves with training clinicians to care for individuals with MR/DD in community settings.

Two landmark events in the evolution of the rights of individuals with disabilities were the passage of the Americans with Disabilities Act in 1990 and the United States Supreme Court decision in *Olmstead vs. L.C.* (1999). These events increased pressure to integrate persons with mental retardation and developmental disabilities into community settings and activities. A community-based infrastructure was created, including new residential opportunities and educational, vocational, recreational, and social supports, but there was no parallel effort to ensure that a system of health care would be available for these individuals. Deinstitutionalization continued, but there were few community practitioners ready to provide care for these patients. In a study by Strauss et al., it was concluded that lack of medical knowledge and experience may have contributed to increased morbidity and/or mortality of previously institutionalized adults with developmental disabilities living in communities.⁵ As former Surgeon General David Satcher pointed out in the *Closing the Gap* report, “as our system of care for those with mental retardation evolved, our attention to their health needs lessened.”

Demographic Trends

The dramatic increase in the life expectancies of individuals with MR/DD has compounded the effect of deinstitutionalization. For example, in the 1960s the average life expectancy for a child with Down Syndrome was three to four years. Today it is fifty-five years, with many living into their sixties and seventies.⁶ Current data suggests that children with MR today will have close to a normal life span.⁷ For more rare syndromes, such as Patau’s syndrome (trisomy 13), textbooks still describe an average life expectancy of 2.5 days (95 percent mortality within first six months),⁸ yet some patients are now living well into their twenties and thirties. With major ad-

vances in medical care, people with developmental disabilities are enjoying longer, healthier lives. This desired outcome has also caused a fundamental demographic shift from a primarily pediatric population to an adult one.

Adolescent Transition Issues

Prior to this time, developmental disabilities were mainly a pediatric concern. Consequently, training in developmental disabilities was limited to subspecialties such as developmental pediatrics and pediatric dentistry—a focus that remained while there were residential systems for adults and the expectation of shortened life span. However, as more children survived into adulthood and remained with their families or in other community settings, mounting concerns developed over the transition of these adolescents into adult health care systems. These concerns were addressed in a series of federally sponsored conferences in 1984 and 1989.^{9,10} In 2002, organizers of the most recent federal conference on adolescent transition decried the lack of progress over the past two decades.¹¹ Following that conference, a consensus statement was issued jointly by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine calling for attention to the transition issues and outlining steps to facilitate the transition to practitioners who provide adult care. However, that plan did not provide a training agenda. Yet one of the biggest barriers to care is the lack of adequately trained dentists and physicians to whom these young patients can be transferred. Of necessity, some pediatric dental and medical providers continue to follow their patients as adults, although they have not received specialty training in adult medical and dental care. The American Dental Association has also taken a position on the importance of practitioners caring for the population of patients for whom they were trained.

Access and Policy Barriers

Together, deinstitutionalization and the aging of this population have created an access crisis for adults with MR/DD. In addition to the lack of trained medical and dental practitioners to see these patients, there are problems with the Medicaid system. The majority of individuals with developmental disabilities are on Medicaid. Yet in twenty-four states, Med-

icaid provides no dental coverage or only emergency dental coverage.¹² These provisions are woefully inadequate to meet the preventive and restorative oral health needs faced by people with disabilities. Medicaid reimbursements are low, particularly when the extra time needed to obtain a history and consent and provide treatment for individuals with MR/DD is considered. These extra demands may discourage clinicians who have no training or experience in the care of these patients.

Even when patients and families can pay for their own dental care, it may still be difficult to find willing providers. In a recent survey of people with developmental disabilities, 47 percent of respondents had trouble obtaining dental care.¹³ Some organizations have attempted to alleviate this by creating provider “databases” of dentists willing to provide such care. In one such database, twenty-six states had no dentists willing to be listed as providing care for patients with developmental disabilities. Of those states with dentists listed, most had fewer than five willing to provide care.¹⁴ Although more dentists may actually provide care for these patients than these numbers suggest, the unwillingness to be listed complicates patients’ and families’ task of identifying appropriate services.

There are also patient-related factors that interfere with access, including limited mobility and access to transportation, muscle spasticity and positioning problems, behavioral difficulties, dental fears, and limited ability to provide oral self-care. These barriers assume greater significance in view of medical risk factors for oral disease in this population.

Oral-Systemic Interactions

Although many oral-systemic interactions have been reported in patients with MR/DD and other special health needs, it is only recently that such interactions have received national attention.^{15,16} Nonspecific inflammatory measures, such as the C-reactive protein, may be markers for cardiovascular disease.¹⁷ One potential source of inflammation that is being examined carefully is periodontal disease, common in the general adult population, but especially those with MR/DD, primarily because of difficulties with oral hygiene. Gingival overgrowth, secondary to use of anticonvulsants,¹⁸ further increases the risk of periodontal disease. Other known examples of oral-systemic interactions include bacterial endocarditis due to oral infections in susceptible patients, such as those with cardiac defects.¹⁹

Poor oral health can also be associated with aspiration pneumonia. One prospective study in a nursing home demonstrated that poor oral hygiene was significantly associated with subsequent development of pneumonia, while an abnormal videofluoroscopic swallowing study, which clearly demonstrated aspiration, was not; only “dependency on caregivers for feeding” and “poor oral hygiene” were predictors of pneumonia.²⁰ Poor oral hygiene can place a person at risk for repeated episodes of pulmonary infection and subsequent chronic lung disease. There are many medications that are commonly prescribed for the elderly that have xerostomia and other oral health side effects including antidepressants, antihypertensives, and a host of others.²¹ Clearly, “dental” conditions can affect systemic health, and “medical” conditions can affect oral health.

Need for Dental-Medical Collaboration

As the general population and individuals with MR/DD live longer, the incidence of chronic diseases and the need for medical therapies will increase oral-systemic interactions. Under these circumstances, the importance of promoting oral health and preventing disease becomes critical. To promote oral health in this population will require interprofessional collaboration: physicians should become advocates for good oral health, and dentists should become more aware of medical conditions that affect oral health.²²

Collaboration between medical and dental providers can also produce useful clinical advances. For example, one study reported improved periodontal health for patients in an interdisciplinary team environment in which anticonvulsant therapeutic choice was influenced by the need to maintain oral health.²³ Dental and medical professionals at the University of Medicine and Dentistry of New Jersey/Robert Wood Johnson Medical School developed a tool called the Lower Incisor Periodontal (LIP) Score for primary care physicians to grade degree of plaque/calculus accumulation on the lower central and lateral incisors. The LIP Score can be used to determine need for dental referral and to monitor the return to a normal score. This tool has been piloted, but further work is needed.²⁴ With cross-disciplinary training and interaction, physicians could screen for common oral diseases like periodontal disease and caries; clearly, intensified training of dental professionals must parallel physician training.

Gaps in Dental Education

What is the status of dental education in the care of special needs populations? Three surveys of dental schools document the absence of an adequate curriculum for predoctoral students. The average number of lecture hours devoted in the curriculum actually decreased from 12.9 in 1993 to five in 1999 with 65 percent of dental schools reporting ten hours or less of clinical instruction.²⁵⁻²⁷ In this educational environment, future dentists will have difficulty developing the skills necessary to provide health care services for this vulnerable population. In addition, dentists choosing academic careers will not be well prepared to provide instruction or direct research agendas for this population. In a recent address to his assembled faculty, Dean Robert Uchin of Nova Southeastern College of Dental Medicine put it this way: “Not only do we not have enough doctors to care for patients with developmental disabilities; we don’t have enough teachers to teach the doctors to care for patients with developmental disabilities.” With a few exceptions, the dental education infrastructure is largely bereft of expertise in this area.

One exception to the lack of academic focus on dental care of patients with MR/DD is the West Virginia University School of Dentistry. In 1979 this school developed a mandatory undergraduate curriculum in care of special patients that included both a semester of didactic instruction and a full year of clinical training. Students provided comprehensive dental services for two to four patients with special needs (about thirty hours) and rotated through other clinics: genetics, hematology, oncology, neurology, cardiology, and cleft palate clinics. These rotations allowed each dental student to be exposed to forty to fifty patients with a variety of disabilities. The didactic components addressed concerns for persons with disabilities in society, dentistry’s role in the habilitation of these persons, specific disabling conditions and associated dental diseases, dental management of patients with disabilities, and maintenance of oral health. To our knowledge only a handful of other dental schools have substantial programs in special needs dentistry. These include the University of Washington, University of Florida, Ohio State University, University of Louisville, Nova Southeastern University, University of Medicine and Dentistry of New Jersey, and Boston University.

Innovations in Dental Education: Developmental Medicine and Developmental Dentistry Fellowships

A major goal of the American Academy of Developmental Medicine and Dentistry (AADMD) is the development of models for dental and medical education that can be adapted across states. Since one of the barriers toward reaching this goal is the geographical fragmentation and isolation of experts in the field, AADMD first assembled experts in this field from around the country. In a number of cases, these experts are the only people in their region treating these patients or engaging in teaching or research focused on this population. In the past year, AADMD has considered a variety of training programs that span the scope of physician and dentist training, from two-week medical student rotations to one-year, PGY-2 (postgraduate year 2) developmental dentistry fellowships. From this review, the AADMD has developed a hybrid education-service model that can simultaneously address many of the problems faced by patients with developmental disabilities.

AADMD's National Action Strategy now focuses on the goal of establishing a series of University-Based Developmental Medicine and Dentistry Programs (UDMDPs) in medical and dental schools. Utilizing pre-existing, community-based primary care clinics, intermediate care facilities (ICFs), and other private service delivery systems (such as the Special Olympics Healthy Athletes program), these training programs will offer fellowships for dentists who have completed a year of hospital dentistry or physicians who have completed residencies. The UDMDP model described in this article is a hybrid of several successful programs already created in New Jersey, Kentucky, Massachusetts, and Virginia. This model has already won awards for its ingenuity in promoting collaborations and partnerships.

The UDMDP model has the potential to address several short- and long-term goals simultaneously. The goals of this model are to:

- **Improve access** to quality medical and dental care for people with MR/DD living in communities and institutions;

- **Address critical education gaps** by functioning as university-based centers of training for medical and dental students, residents, fellows, and community practitioners;
- **Promote patient-centered research** on medical and dental problems affecting patients' quality of life and increasing the evidence base behind current clinical care; and
- **Encourage partnerships** between dental and medical practitioners and among universities and community sites, advocates, and families.

It is worth noting that the UDMDP model optimizes cost and time outcomes. By utilizing pre-existing physical infrastructure, this model keeps costs down and allows programs to be established with minimal expenditure and in a relatively short time period. Additionally, the UDMDP model encourages long-lasting partnerships. These partnerships will improve the quality of education in developmental disabilities by moving experienced clinicians into academic positions, as well as the quality of patient care by bringing new graduates and new science to these clinical settings.

Curriculum in Developmental Dentistry

To support the realization of these centers, AADMD, in cooperation with Special Olympics, *EP (Exceptional Parent) Magazine*, the American Academy of Pediatric Dentistry, and the Voice of the Retarded, has embarked on the task of creating a nationally consistent, quality curriculum that can be adapted to any medical or dental school and tailored to undergraduate or postgraduate level needs. The AADMD is identifying dental schools with existing curricular components and those willing to implement a more fully developed curriculum. This effort has been strategically planned in anticipation of a hoped-for decision by the Commission on Dental Accreditation (CODA) that would mandate special needs curriculum as part of required dental education. The Proposed Standard 2-26 developed by CODA for consideration states that "graduates must be competent in assessing the treatment needs of patients with special needs." The supplementary Intent Statement adds that an "appropriate patient pool should be available to provide a wide scope of patient experiences that include patients whose medical, physical, psychological, or social situations make it necessary to modify dental routines in order to pro-

vide dental treatment for that individual.” A vote on the proposed standard is scheduled during CODA’s January 2004 meeting.

In 2002, the American Dental Association (ADA) adopted a resolution supporting access to oral health care for persons with special needs.²⁸ This resolution directs the ADA to support appropriate initiatives and legislation to improve the oral health of persons with special needs and encourages similar action at the state and local levels. This resolution also challenges dental and allied dental programs to educate students about the oral health needs and issues of people with special needs. (See proposed didactic elements and goals and objectives for a fellowship in developmental dentistry, Tables 1 and 2.)

Best Practices

The prototype of the UDMDP fellowship in “Developmental Dentistry” has been created at the University of Louisville School of Dentistry. This fellowship was awarded the 2003 Centers for Medicare and Medicaid Services Beneficiary Services Certificate of Merit for establishing a partnership between the University of Louisville School of Dentistry, Hazelwood Center Intermediate Care Facility, and the Underwood and Lee Clinic. It includes the elements of community-based patient care, teach-

ing, and research. This one-year, postgraduate training program in developmental dentistry is open to fellows who have successfully completed one year of postgraduate training in hospital dentistry.

Another model interdisciplinary program focusing on the need for physician training in this area has evolved at the University of Medicine and Dentistry of New Jersey/Robert Wood Johnson Medical School. To address the problem of health disparities encountered in adults with mental retardation, the Department of Medicine established a specialized program in 1998 designated the “Developmental Medicine Program.” Subsequently, collaborations were established with agencies and groups that regularly confronted health issues of adults with mental retardation, but did not traditionally collaborate. Specialized clinics and training programs were established by the Developmental Medicine Program, and during a three-year period these clinical facilities were able to support specialized services for 200 adults with mental retardation and complex medical problems, training for forty-three medical residents, and a special intensive elective for five medical residents. Drawing on the success of this experience, the Department of Medicine is now also offering a formal fellowship for postgraduate physicians in the field of adult developmental disabilities. Unique to

Table 1. Didactic curriculum from the developmental dentistry fellowship

- Essential Concepts of Developmental Medicine and Dentistry
 - Genetics and Neurodevelopmental Disorders
 - Behavior Management Techniques
 - Examination, Diagnosis, and Treatment Planning
 - Dental Implications of Neurodevelopmental Disability
 - Quadrant Dentistry/Hospital Dentistry
 - Fundamentals of Supportive Respiratory Care
 - Comprehensive Dentistry Under General Anesthesia
 - Including the Family in the Planning of Care
 - Understanding Social, Political, and Legal Factors
 - Fundamentals of Practice Management
 - Acquired Disability: Traumatic Brain Injury, CVAs, Others
 - Dental Care of the Psychiatric Patient
 - Dental Care of the Geriatric Patient
 - Dental Care for Patients with Sensory Impairment
 - Essential Concepts in Pharmacy
-

Table 2. Developmental dentistry fellowship goals and objectives

- Understand the fundamental impact that developmental disability has on dental health and dental care.
 - Perform effective comprehensive examinations; develop accurate diagnoses and write individualized plans of care for medically fragile, developmentally disabled pediatric and adult dental patients.
 - Solve the problems associated with the clinical care of developmentally disabled dental patients, which create obstacles to the safe and effective delivery of services.
 - Function as the developmental disabilities dental specialist in multiple dental and medical arenas.
 - Create a research, publishing, and lecture effort as a basis for teaching, expanding professional advocacy, and improving the general standard of care.
 - Accept the essential responsibilities of professional citizenship.
-

this program is the inclusion of oral health training and presence of dental faculty within the Department of Internal Medicine. This program is actively involved in research in behavioral and other oral health issues.

In October 2003, a full-service special needs dental clinic opened within a family practice center (the Warren Community Hospital/Coventry Family Practice Center Adaptive Dental Clinic for Patients with Special Needs). This unique model provides a convenient “in-house” site for the training of twenty-four family practice residents in oral health. This training site is also developing collaborations with regional dental schools and dental residency training programs for purposes of further cross-training of medical/dental students and residents.

Partnerships

While the dialogue between a single doctor and family can have an impact on the health of a single patient, a dialogue between a national academy of developmental dentists and physicians and a readership of half a million concerned family members can affect the health of many. To this end, an important part of AADMD’s strategy has been to develop partnerships with key advocacy groups. In particular, AADMD is partnering with *EP (Exceptional Parent) Magazine* to reach out to the parents and families of people with developmental disabilities. The academy has also worked closely with Special Olympics, Inc., an organization that for years has had an interest in and played a leadership role in advocating for the health of people with mental retardation.

Summary and Conclusions

Deinstitutionalization and an increasing life expectancy have created a crisis in access to health care for adults with MR/DD. These societal trends have not been accompanied by needed changes in dental and medical training to include an emphasis on special needs patients for practitioners caring for adults. The severity of observed disease in this population drives the need for action.

One of the first steps necessary to improve training is the recognition of the critical importance of dentist/physician collaboration in the care of pa-

tients with MR/DD. This recognition must be followed by mechanisms and opportunities for such collaboration. It is important for physicians and dentists to view each other as colleagues with a common purpose and as reciprocal sources of professional strength and support.

Substantial progress toward eliminating health disparities for persons with MR/DD will also require that all medical and dental schools incorporate appropriate curriculum at the undergraduate level. In addition, more fellowships in developmental dentistry and medicine must be implemented and evaluated. The desired goal is to extend accepted, high standards of health care to individuals with MR/DD wherever they reside. University-Based Developmental Medicine and Dentistry Programs can accomplish these goals by a critical partnership of university and community facilities. These partnerships will strengthen our societal commitment to people with developmental disabilities and make it more difficult for any one of the partners to turn away from their commitment in years to come.

Eliminating oral health disparities for this population also requires further development of an evidence base for clinical care, including important oral-systemic interactions. The timing is ripe for such changes, with the recent announcement of a concept clearance for Clinical Research to Improve Oral Health of Special Needs Populations and the Elderly by the National Institute for Dental and Craniofacial Research (NIDCR).²⁹ Concepts approved by the NIDCR represent early planning stages for initiatives in which the NIDCR seeks to support research in an understudied and significant area of science. While clearance of a concept by the NIDCR does not guarantee that a concept will become a request for grant proposals, this possibility is significantly increased.

The establishment of the AADMD represents, in many ways, a first, critical step towards accomplishing many of these goals. It is, in our minds, a model of professional collaboration, with dentistry and medicine together accepting the professional responsibility to advance care and knowledge for a vulnerable population. The AADMD principals will help in whatever ways possible to provide support, content, and expertise to similar efforts wherever they are occurring and call upon academicians, clinicians, and researchers to join them in this effort.*

*For more information about the AADMD, visit www.aadmd.org. Information about Special Olympics Special Smiles program can be found at www.specialolympics.org. For information about online educational seminars endorsed by the AADMD, visit www.exceptionalparent.com. For advocacy information about other issues concerning people with developmental disabilities, visit www.aamr.org and www.vor.net.

REFERENCES

1. Closing the gap: a national blueprint to improve the health of persons with mental retardation. At: www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf. Accessed: October 14, 2003.
2. 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. At: www.nidcr.nih.gov/sgr/oralhealth.asp. Accessed: November 8, 2003.
3. National call to action to promote oral health. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Institute of Dental and Craniofacial Research, Spring 2003. NIH Publication No. 03-5303. At: www.nidcr.nih.gov/sgr/CallToAction.asp. Accessed: November 8, 2003.
4. Braddock D, Hemp R, Bachelder L, Fujiura G. The state of the states in developmental disabilities, 4th ed. Washington, DC: American Association of Mental Retardation, 1995:10.
5. Strauss D, Kastner T, Shavelle R. Mortality of adults with developmental disabilities in California institutions and community care, 1985-1994. *Ment Retard* 1998;36:360-71.
6. The National Association of Down Syndrome. Fact sheet. At: www.nads.org/pages/facts.htm. Accessed: November 4, 2003.
7. Janicki MP, Dalton AJ, Henderson CM, Davidson PM. Mortality and morbidity among older adults with intellectual disability: health service considerations. *Disabil Rehabil* 1999;21:284-94.
8. Jones, KL. Smith's recognizable patterns of human malformation. 5th ed. Philadelphia: W.B. Saunders Co., 1997:18-9.
9. McGrab P, Millar J, eds. Surgeon general's conference: growing up and getting medical care: youth with special health care needs. Washington, DC: National Center for Networking Community Based Services, Georgetown University Child Development Center, 1989.
10. Blum RW. Transition to adult health care: setting the stage. *J Adolesc Health* 1995;17:3-5.
11. American Academy of Pediatrics. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care (conference proceedings). Blum RW, ed. *Pediatrics* 2002;110(6 pt 2):1301-3.
12. Oral Health America report card, 2003:15. At: [www.oralhealthamerica.org/Report percent20Card percent202003 percent20final.pdf](http://www.oralhealthamerica.org/Report%20percent20Card%20percent202003%20percent20final.pdf). Accessed: November 4, 2003.
13. Special Olympics report. Hearing before a subcommittee of the committee on appropriations, United States Senate. 117th Congress, 1st Session. Special Hearing. March 5, 2001.
14. Matthew Holder, unpublished data, 2003.
15. Chapter 5, linkages with general health. In: Oral health in America: a report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, National Institute of Dental and Craniofacial Research, National Institutes of Health, 2000. At: www.nidcr.nih.gov/sgr/sgrweb/chap5.htm. Accessed: November 8, 2003.
16. Slavkin HC, Baum BJ. Relationship of dental and oral pathology to systemic illness. *JAMA* 2000;284:1215-7.
17. Ridker P. Beyond cholesterol: crp and inflammatory markers for cardiovascular disease. *Resident and Staff Physician* (supplement) 2003;49:16-21.
18. Karolyhazy K, Kovacs E, Kivovics P, Fejerdy P, Aranyi Z. Dental status and oral health of patients with epilepsy: an epidemiologic study. *Epilepsia* 2003;44(8):1103-8.
19. Okuda K, Ebihara Y. Relationships between chronic infectious diseases and systemic diseases. *Bull Tokyo Dent Collection* 1998;39(3):165-74.
20. Langmore SE, et al. Predictors of aspiration pneumonia: how important is dysphagia? *Dysphagia* 1998;69-81.
21. Byrne BE. Oral manifestations of systemic agents. In: ADA guide to dental therapeutics. Chicago: American Dental Association, 2000.
22. Mouradian WE. A physician viewpoint on the oral health of children. *Dent Abstracts* 2000;45:252-3.
23. Nichols J, Farman AG, Gruenthal M, Hood H. Substitution of Topamax anti-seizure regimen for Dilantin in patients with mental retardation and developmental disability. University of Louisville Research, 2003. Presented at the 32nd Annual Meeting and Exhibition of the AADR, San Antonio, TX, March 12-15, 2003.
24. Maggio J, May P, Perlman S. The lower incisor periodontal (LIP) score: a dental screening tool for primary care physicians. *EP Magazine* 2003;33(3):101-3.
25. Fenton SJ. 1993 survey of training in the treatment of persons with disabilities. *Interface* 1993;9(7):1,4.
26. Fenton SJ. People with disabilities need more than lip service. *Spec Care Dent* 1999;19(5):198-9.
27. Romer M, Dougherty N, Amores-Lafleur E. Predoctoral education in special care dentistry: paving the way to better access. *ASDC J Dent Child* 1999;66(2):132-5.
28. American Dental Association, Resolution 66H, Access to Oral Health Care for Persons with Special Needs, passed, New Orleans, October 2002.
29. U.S. Department of Health and Human Services, National Institutes of Health, National Institute for Dental and Craniofacial Research. Clinical research to improve oral health of special needs populations and the elderly by research. At: www.nidcr.nih.gov/funding/concept/special_needs_populations.asp. Accessed: November 8, 2003.