

Access to Oral Health Care for Florida's Citizens with Developmental Disabilities

**Prepared by: The University of Florida College of Dentistry
and Nova Southeastern School of Dental Medicine**



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From the Council

For many years, individuals with developmental disabilities, their families, caregivers and friends have been concerned about the lack of availability of quality oral health care in communities throughout Florida for citizens with developmental disabilities. This concern prompted the Council to seek out information on the status of oral health care in this state. We commissioned the University of Florida School of Dentistry and Nova Southeastern University School of Dental Medicine to provide us with information on why this lack of access exists.

My own son, despite many oral challenges, has been fortunate to have wonderful, caring dentists who have provided excellent care. However, in talking to other families, our experience has been the exception. Many families have no access to oral health care and this lack of access creates numerous health problems for individuals with developmental disabilities.

This white paper gathers information and separates fact from supposition. It is the first step in our quest to ensure oral health access for individuals with developmental disabilities. It provides us with information on the barriers to access and recommendations for the future. It looks at everything from reimbursement rates in Medicaid to lack of training and experience and, in some cases, lack of compassion.

Professionals, who teach in our two dental universities and have for many years worked daily with individuals with developmental disabilities, wrote this white paper. It contains input from the Council's Health Care and Community Living task forces as well as numerous other professionals in the field. It documents individual experience and expectations and includes family concerns, as well as recommendations for action.

There was a time when individuals with developmental disabilities were separated from their homes and communities to live in isolated settings. Fortunately, those days are past and we realize that diverse communities that include all citizens as valuable participants are vital communities. Participating in a community means more than a home and a job, it also includes the ability to utilize the many services in a community including access to quality dental care.

Realizing that long-term solutions are often not overnight fixes, we view this report as a first step in addressing this complex issue. We hope that it will also be a first step in partnering with the dental community to build a quality oral health system for all citizens of Florida.

Lou Piotrowski, Chair
Florida Developmental Disabilities Council, Inc.
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Joint-Committee: Advisory Members

Anne di Napoli, President, Gulf Coast Autism Association, Inc.

Thomas P. Floyd, D.M.D., Florida Dental Association.

Arlene Hechter Lakin, Esq., Founder and President, Florida's Voice on Mental Retardation.

Nicky Moulton, Medicaid Program Development, Florida Agency for Health Care Administration.

Nan H. Rich, Chair, Children's Services Board of Broward County.

Waldo Scales, D.D.S., Florida Dental Association.

Tonie Vogt, Program/Policy Manager, Health Care & Prevention, Florida Developmental Disabilities Council.

Susan White, Ph.D., M.S.N., Vice President Quality Management, Florida Hospital Association.

Joint-Committee: University Members

Paul Burtner, D.M.D., Project Director, Associate Professor, Department of Pediatric Dentistry, University of Florida College of Dentistry.

Frank Courts, D.D.S., Ph.D., Principal Investigator, Associate Professor and Chair, Department of Pediatric Dentistry, University of Florida College of Dentistry.

John D. Tabak, D.D.S., M. S., Associate Professor and Chair, Department of Community Dentistry, Nova Southeastern University College of Dental Medicine.

Robert A. Uchin, D.D.S., Dean, Nova Southeastern University College of Dental Medicine.

White Paper Authors:

Paul Burtner, D.M.D., Project Director, Associate Professor, Department of Pediatric Dentistry, University of Florida College of Dentistry.

Frank Courts, D.D.S., Ph.D., Principal Investigator, Associate Professor and Chair, Department of Pediatric Dentistry, University of Florida College of Dentistry.

John D. Tabak, D.D.S., M. S., Associate Professor and Chair, Department of Community Dentistry, Nova Southeastern University College of Dental Medicine.

Robert A. Uchin, D.D.S., Dean, Nova Southeastern University College of Dental Medicine.

White Paper Reviewers:

Thomas F. Floyd, D.M.D., Florida Dental Association.

Timothy P. Garvey, D.M.D., Clinical Assistant Professor, Department of Pediatric Dentistry, University of Florida College of Dentistry.

Arlene Hechter Lakin, Esq., Founder and President of Florida's Voice on Mental Retardation.

Lara Oon, D.D.S., Clinical Assistant Professor, Department of Pediatric Dentistry, University of Florida College of Dentistry.

Steve Perlman, D.D.S., Associate Clinical Professor Dentistry, Goldman School of Graduate Dentistry, Boston University.

Waldo Scales, D.D.S., Florida Dental Association.

Tonie Vogt, Program/Policy Manager, Health Care and Prevention, Florida Developmental Disabilities Council.

Susan White, Ph.D, M.S N., Vice President Quality Management, Florida Hospital Association.

Other Contributors:

Arnold M. Cukier, D.D.S., President, Spina Bifida Association of Florida.

Harry Davis, D.D.S., Dental Executive Director, Public Dental Health Program, Florida Department of Health.

Millard Howard, D.D.S., Dental Program Analyst, Agency for Health Care Administration.

Dora Rodriguez, D.D.S., Pediatric Dentist, Department of (Community) Dentistry, Nova Southeastern University College of Dental Medicine.

Denise Vedrenne, D.D.S., Chair, Department of Pediatric Dentistry, Nova Southeastern University College of Dental Medicine.

Debra Vitale, R.D.H., B.S., President, Florida Dental Hygiene Association.

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Introduction of Issue

Access to oral health care for many of Florida's citizens with developmental disabilities is inadequate. The resulting lack of care places people with developmental disabilities at risk for oral diseases, as well as systemic disorders. Consequently, many of Florida's citizens with developmental disabilities, both children and adults, experience orofacial pain and discomfort. Oral conditions commonly observed in this special population include: chronic toothaches from decayed teeth; missing and loose teeth; chipped and fractured teeth; loss of supporting bone structure; dental abscesses; malocclusion and misaligned teeth; and, compromised esthetics due to missing anterior teeth. Parents report that when oral health care is not provided, these individuals suffer from seizures, malocclusions, tooth grinding and pain evidenced by grimacing. People who cannot communicate their discomfort are at greatest risk and may needlessly suffer from severe dental pain that may go undetected for long periods of time. If left untreated, these conditions can result in self-injurious or aggressive behavior. Moreover, the lack of appropriate daily preventive care, including education about oral hygiene and disease control, creates a continuing health problem for this special population.

Oral diseases may have a detrimental effect on one's self-esteem, social interaction, education, career achievement and emotional state. Clearly, poor oral health can and does have a significant negative impact on a person's quality of life.

*“When health is absent,
Wisdom cannot reveal itself,
Art cannot become manifest,
Strength cannot fight,
Wealth becomes useless,
And intelligence cannot be applied.”*

— Herophiles, 300 BC

The Florida Developmental Disabilities Council commissioned this study with the two dental universities in Florida, the University of Florida and Nova Southeastern University, to better understand the issue of access and to ensure that this segment of Florida's population gains access to comprehensive quality oral health care, including care from dental specialists. In this process, we received input from parents, the Florida Dental Association, Florida Hospital Association, Florida Dental Hygiene Society, community oral practitioners, Florida state agency representatives, and other professionals in the country, as well as experienced university providers working in the clinics.

The objectives of this study are: 1) to investigate the problem of lack of access to dental services and its consequences for Florida's citizens with developmental disabilities, 2) to identify the causes of this problem, 3) to present potential solutions to the problem of lack of access, such as identifying potential providers, and 4) to make specific recommendations to the Council.

Methodology

This section describes the process by which the white paper on Access to Oral Health Care for Florida's Citizens with Developmental Disabilities was developed. The project was initiated when the Florida Developmental Disabilities Council contracted with the Nova Southeastern University College of Dental Medicine and the University of Florida College of Dentistry to manage the process that would result in a white paper describing issues related to access to oral health care and the detrimental consequences of poor oral health experienced by individuals with developmental disabilities. In addition, the white paper was to present recommendations for establishing a statewide oral health care delivery system designed to ensure that comprehensive oral health care is available to all of Florida's citizens with developmental disabilities.

The first task was to establish an advisory committee to contribute oversight and direction to the Working Group, which was composed of representatives of the two colleges who were responsible for completing the project. The Advisory Committee was composed of parents, representatives from the practicing dental community who were recommended by the Florida Dental Association, other health care providers with expertise in providing dental care to this special population, and representatives of governmental and private agencies which provide assistance to people with developmental disabilities.

To enhance efficiency and communication, the Advisory Group and the Working Group were combined to create the "Joint-Committee." The Joint-Committee reviewed the relevant literature to acquire a broad perspective on the problems encountered in accessing oral health care for people with developmental disabilities, and the wide variety of solutions that have been developed to address these concerns. The Joint-Committee interviewed and held discussions with a number of individuals with an interest in finding solutions to the lack of access, including parents and care-providers, advocacy groups, health care providers such as hospitals, individual providers such as dentists who provide care to people with developmental disabilities, and other interested parties.

The preliminary drafts of the white paper were prepared and discussed by the various constituencies at several stages of development. Based on the findings of the literature review, much deliberation and discussion, and the many years of professional and personal experience acquired by the Joint-Committee members, the Joint-Committee developed recommendations designed to establish an effective care delivery system which, if fully implemented, should ensure access to oral health care for all of Florida's citizens with developmental disabilities.

Executive Summary

The Problem

Access to oral health care for many of Florida's citizens with developmental disabilities is inadequate. The resulting lack of care places people with developmental disabilities at risk for oral diseases, systemic disorders, and leads to pain and discomfort and has a significant negative impact on their quality of life. The Florida Developmental Disabilities Council commissioned this study to assist it in developing strategic goals and initiatives to ensure that this segment of Florida's population gains access to comprehensive oral health care.

An estimated 533,500 Florida residents have mental retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome, the conditions defined by law as "developmental disabilities." Only 32,500 of them received services from Florida's Department of Children and Families during 2000 and approximately 29,100 live in community settings. The vast majority of this population is dependent upon the community-based private health care system for primary and preventive medical and dental care.

Although a national problem, for Florida's citizens with developmental disabilities, dental care is the most difficult service to access. There appears to be an adequate number of licensed dentists in Florida to meet the present level of demand for dental services; however, there are not enough practitioners willing to provide care to people with developmental disabilities.

For the foreseeable future, the trend to normalize and deinstitutionalize people with developmental disabilities and support them in home-like community residential settings will continue. Increasing numbers of individuals will require oral health care and general health care that is coordinated with their systemic and disabling conditions.

Barriers

Citizens with developmental disabilities and their advocates face a number of barriers when attempting to obtain comprehensive dental care. The perception in the dental profession is that one cannot make a living treating persons with disabilities. Medicaid reimbursement fees are inadequate, and Dental Insurance Plans are often inadequate for the needs of the developmentally disabled and too costly for the working disabled. The Americans with Disabilities Act makes it illegal to charge more than one's usual fee to a special needs patient, even though more procedures are required for treatment.

In addition, behavior management issues many times require sedation or behavior modification techniques. Successful treatment of developmentally disabled patients can involve immobilization, sedation and anesthesia techniques that many dentists have not learned and special equipment they do not have. Most dentists are unwilling to assume those financial burdens in the face of so much patient funding uncertainty. Informed consent and guardianship issues are a constant stumbling block in the practices of those who are willing and able to provide care.

Prevention programs and basic services must be available in local communities. In order to accomplish this goal, the pre-doctoral education of oral health care professionals must be enhanced. Additionally, facilities for the individual who is severely and profoundly disabled must be provided outside of the private office environment.

Recommendations

A comprehensive statewide oral health care delivery system for citizens with developmental disabilities should include each of the following elements:

- A community-based primary oral health care program in which quality services are provided by private practitioners.
- Regional educational and service centers which support community-based practitioners by providing adequate education and training in the provision of special care to people with developmental disabilities.
- Reimbursement mechanisms that provide oral health care professionals with a fee level commensurate with the expertise, time and staffing needed to provide care to people with developmental disabilities, especially the more difficult cases.
- Incentives for hospitals and other health care professionals to participate in these important and costly treatment programs.

We recommend the establishment of two Centers of Excellence: one at the University of Florida College of Dentistry and one at the Nova Southeastern University College of Dental Medicine. These Centers of Excellence will provide treatment for the most complex patients, train the next generation of oral health care professionals who will be providing primary care to people with developmental disabilities, and conduct continuing education programs necessary to train community practitioners in the provision of care for these individuals.

Additionally, we recommend the establishment of five Regional Centers for the provision of care for this special population. We believe the most appropriate locations for the Regional Centers are Pensacola, Jacksonville, Orlando, Tampa and Miami. The focus of the Regional Centers would be to support the community practitioners and provide care to individuals who are more difficult to treat.

For the Centers of Excellence and Regional Centers to meet their goals, funding for an experienced full-time dentist and at least two dental assistants should be provided. Funding for services provided in the hospital setting should be included.

Each Center must work in partnership with organizations such as the Florida Department of Children and Families, the Association of Retarded Citizens, Florida's Voice on Mental Retardation, the Florida Dental Association and the Florida Developmental Disabilities Council to meet the needs of citizens with developmental disabilities. Finally, there should be an executive level position to oversee and coordinate the efforts of all seven Centers and possibly a Board of Directors.

Community practitioners must be reimbursed at levels appropriate for the time, effort, expertise and staffing required to provide care for this special population. Once the community dentists are trained to provide primary care to the residents of their communities, there will still be no incentive to do so, unless there is meaningful reform of the current public and private reimbursement systems.

There is no instant solution. However, if fully implemented, these recommendations should result in an oral health care delivery system that is in harmony with the desires of Florida's citizens with developmental disabilities and the people who care for and support them. It must be recognized that it will take time to phase in all aspects of the proposed program.

Florida's Citizens with Developmental Disabilities and Oral Health Services Report

What is a developmental disability? According to Florida Statutes¹, "...developmental disability means a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely." As a definition, the statute is somewhat inaccurate. More precisely, a disability is defined in terms of limited ability to function. Therefore, a disability is a mental or physical impairment that substantially limits one or more major life activities such as walking, hearing, seeing, learning, or caring for oneself². Impairments may be caused by a variety of disorders such as mental retardation, cerebral palsy, sensory disorders, or paralysis. A disorder is not a disability. A disorder can cause an impairment that, depending on the degree of functional limitation, may or may not be considered a disability.

A "developmental disability" is a mental or physical impairment caused by a disorder occurring during the years of development, birth to age 18. For example, if an 8-year-old child became a paraplegic as a result of trauma, the child would generally be considered to have a developmental disability. However, according to Florida Statutes, such a child would not be considered to have a developmental disability unless the trauma also resulted in mental retardation.

- **How many of these individuals live in Florida and where do they reside?**

Information is lacking about Florida's citizens with developmental disabilities. An estimated 533,500 Florida residents have mental retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome. This estimate is based on incidence data³⁻⁶ and Florida Statutes¹ and is depicted in Table 1.

Disability	Incidence	Individuals
Autism	1/500	30,000
Cerebral Palsy	3/1,000	45,000
Mental Retardation	3/100	450,000
Prader-Willi Syndrome	1/15,000	1,000
Spina Bifida	1/2,000	7,500
Total		533,500

Only 32,500 of Florida's estimated 533,500 residents with mental retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome received services from Florida's Department of Children and Families during 2000. Data regarding individuals receiving services from DCF is readily obtainable; however, there is a paucity of information about the estimated 500,000 people who are not receiving services. This lack of information results in a rather large "hidden population." The authors personally know parents of individuals with severe developmental disabilities who take care of their

children at home, attempt to obtain medical/dental care in the community, and have never contacted the Department of Children and Families to request services. Obviously, this hidden population requires medical/dental services. We know that: 1) many of these individuals are adults, 2) they may exhibit resistant behavior during dental treatment procedures, 3) they experience difficulty in obtaining comprehensive health care in the community, and 4) payment for medical/dental services is a concern for this group. Even when finances are not a concern, access is.

Regarding their place of residence, the past thirty years have seen an increasing trend for both adults and children with developmental disabilities to live with their families or in small, community residential settings instead of large, state-operated institutions, i.e., *Intermediate Care Facilities for Developmentally Disabled (ICF/DD)*.^{7,8} While the percentages vary greatly among states, the average decrease in the number of residents in state-operated institutions (*ICF/DD*) from 1987 to 1997 was 41 percent. This trend is referred to as *deinstitutionalization* or *normalization*. Florida had six Developmental Services Institutions (DSI); two have been closed, and the remaining four have been downsized by as much as 65 percent. Many of the former residents now live in communities throughout Florida.

There are many reasons for this deinstitutionalization trend, including parent advocacy for more community-based programs, recognition of the civil rights of people with disabilities to live and participate in society, legislative mandates to downsize institutions, and the establishment of government programs to support community living arrangements. Government programs include Supplemental Security Income that provides cash benefits and Special Education programs that provide local education for children with developmental disabilities.⁹

Of the 32,500 individuals receiving services from Florida's Department of Children and Families during the past year, approximately 29,100 lived in community settings. Sixteen percent of these individuals lived in homes of their own with support (*assisted living*) and 17 percent resided in group homes, foster homes, or residential habilitation centers. Approximately 1,900 people resided in private institutional facilities, while only 1,500 individuals continued to reside in Florida's four remaining public Developmental Services Institutions. Information is not available for the estimated 500,000 people with developmental disabilities not receiving services from the Department of Children and Families.

• What issues affect the daily lives of people who have a disability?

Some of the issues that affect the lives of people with developmental disabilities are:

Community Living: Are social services available? Is there adequate housing available that accommodates their disabilities? Is financial assistance available?

Because their disabilities restrict communication, mobility, and ability to take care of themselves, people with developmental disabilities may rely on assistance from others. To help meet these needs, federal, state, and local agencies provide health care, vocational training and service coordination to people with developmental disabilities and their families. In Florida, the Developmental Disabilities Program Office of the Department of Children and Families is the major provider of social services. Housing is available from private vendors, private organizations and DCF.

Transportation: Is public or private transportation available? Is it convenient? Who pays for it? Do the vehicles accommodate people with disabilities? Is the bus stop conveniently located? How convenient is the bus route? Is transportation safe and reliable? Can one get to where one needs to go?

A lack of convenient transportation can create a significant barrier that acts to prevent these individuals from accessing needed services. Although this is a very important and relevant issue, a thorough discussion of transportation issues is beyond the scope of this paper.

Education: Is special education available? Can one learn marketable job skills? Who will provide the education? Is the educational center conveniently located? Can one obtain special tutoring if needed?

Education is a critical issue. If provided with an appropriate education that results in marketable skills, many of these individuals could be employed and, potentially, purchase oral health care from community practitioners. This could transcend one of the main barriers they experience in obtaining dental care, i.e., purchasing power. Again, this is very important and relevant; however, a thorough discussion of educational concerns is beyond the scope of this white paper.

Employment: Will employers hire a person with a disability? Are employers willing to make necessary accommodations for a person with a disability? Are medical/dental benefits provided? Is reliable and affordable transportation available?

Some of these individuals are employed, mostly in sheltered workshops. Approximately 24 percent of those who have obtained employment are working in integrated settings (non-sheltered workshops).

On the other hand, many are dependent on others for their “Activities of Daily Living” (ADLs) such as bathing, dressing, using the toilet, eating, preparing meals and managing money. Unfortunately, such individuals may experience difficulty in obtaining employment and often spend their days at home watching television, listening to the radio, or playing with toys. Some of them may assist with housework or run errands. A few spend their time in day care programs.⁹

Health Care: Are medical and dental services available in the community? Are the health care providers sensitive to the needs of people with disabling conditions? Are the health care providers trained to care for people with disabilities? Does the Public Health Department provide care? Is financial assistance available? Is transportation available?

As a consequence of *normalization* and *deinstitutionalization*, individuals who live with their families, or in government-supported community-based residential programs must obtain dental services in their local community from private practitioners, outpatient clinics, hospitals, or surgical centers. Typically, DSI’s are responsible for providing dental care exclusively to residents of the institution. Exceptions to this policy have been implemented at some institutions as discussed later in this report.

• How successful is this segment of the population at obtaining comprehensive oral health care?

Although various specialized social services are available from state agencies for residents of group, foster, and family homes, this population is dependent upon the community-based private health care

system for primary and preventive medical and dental care.¹¹⁻¹⁵ Obtaining comprehensive health care for this special population, however, may prove difficult in some communities due to an inadequate number of health care professionals who are trained, experienced, and willing to provide treatment.^{13,16} Furthermore, services from medical specialists may not be available in every community.¹³

Access to oral health care for people with developmental disabilities is a national problem. Almost two thirds of community-based residential facilities report that inadequate access to dental care is a significant issue.¹⁷ Parents consistently report dental care as one of the most needed services for their children with disabilities, regardless of age.¹⁸ Results of oral assessments of Special Olympics athletes of all ages in the US during 1999 indicate that 12.9 percent of athletes reported some form of oral pain, 39 percent demonstrated signs of gingival infection, and nearly 25 percent had untreated tooth decay (Special Olympics, Inc. unpublished data). It is noteworthy that these athletes tend to be from higher-income families.

For Florida's citizens with developmental disabilities, dental care is the most difficult service to access.¹⁰ In a 1990 survey, 40 percent of caretakers in North Central Florida reported difficulty in locating dentists willing to provide comprehensive dental services for their residents.¹⁹ Also, in a 1992 survey of 659 licensed group home operators who were responsible for the care of approximately 9,000 individuals with developmental disabilities in all regions of Florida, 48 percent reported difficulty in locating dentists willing to treat their residents (Burtner, unpublished study, 1992). Moreover, some people with developmental disabilities are very resistant during dental procedures and may require general anesthesia to receive dental care. Currently, it appears that only one dentist in North Central Florida is providing comprehensive dental care on a regular basis to adults with developmental disabilities while the patient is under general anesthesia (hospital dentistry). The waiting list for this dentist's services is approximately one year.²⁰

According to Chapter 393.066 of Florida Statutes, "The Department of Children and Family Services shall plan, develop, organize, and implement its programs of services and treatment for persons who are developmentally disabled...The goal of such programs shall be to allow clients to live as independently as possible in their own homes or communities and to achieve productive lives as close to normal as possible. Community-based services shall, to the extent of available resources, include medical/dental services". Unfortunately, these services are not available in many communities. Is lack of access to services due to an inadequate number of dentists in Florida?

There are 8,530 dentists who have a Florida license and a Florida mailing address.²¹ As depicted in table 2, Florida has one dentist per 1,718 residents; the national average is one dentist per 1,712.¹⁷

Region	Population	Dentists	Ratio
S. Florida	5,356,042	3745	1430
C. Florida	5,369,370	2912	1844
N. Florida	2,723,032	1334	2041
W. Florida	1,205,501	539	2237
Florida	14,653,945	8,530	1718
U.S.A.	265,189,000	154,900	1712

The geographic distribution of these practitioners is depicted in figures 1 and 2. In South Florida, there is one dentist for every 1,430 citizens, and Central Florida has one dentist per 1,844 residents. However, the ratios in North Florida and West Florida are one dentist per 2,041 and 2,237, respectively.

Figure 1. Dentists per 100,000 residents.

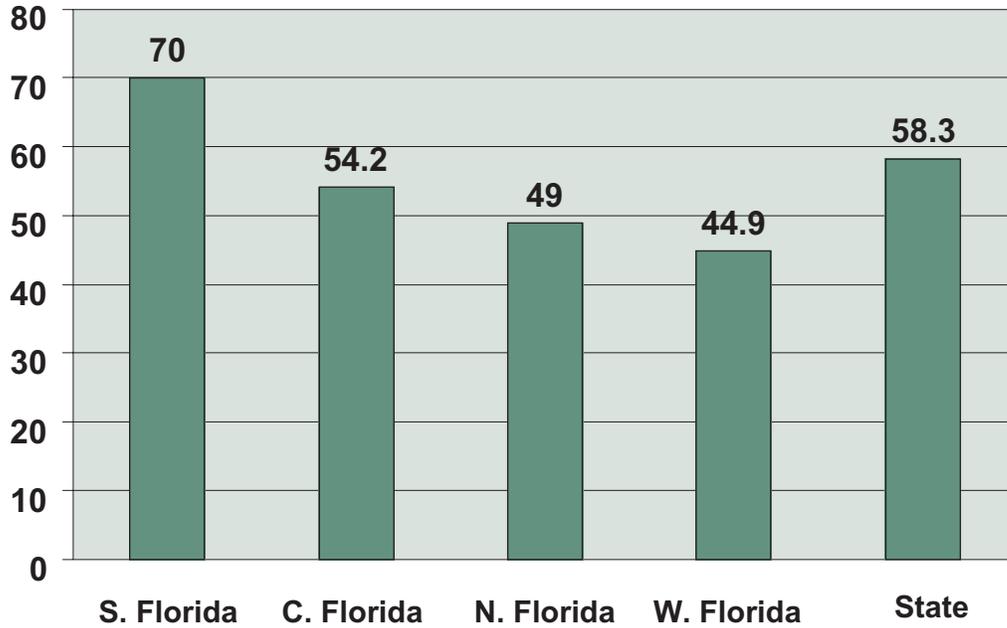
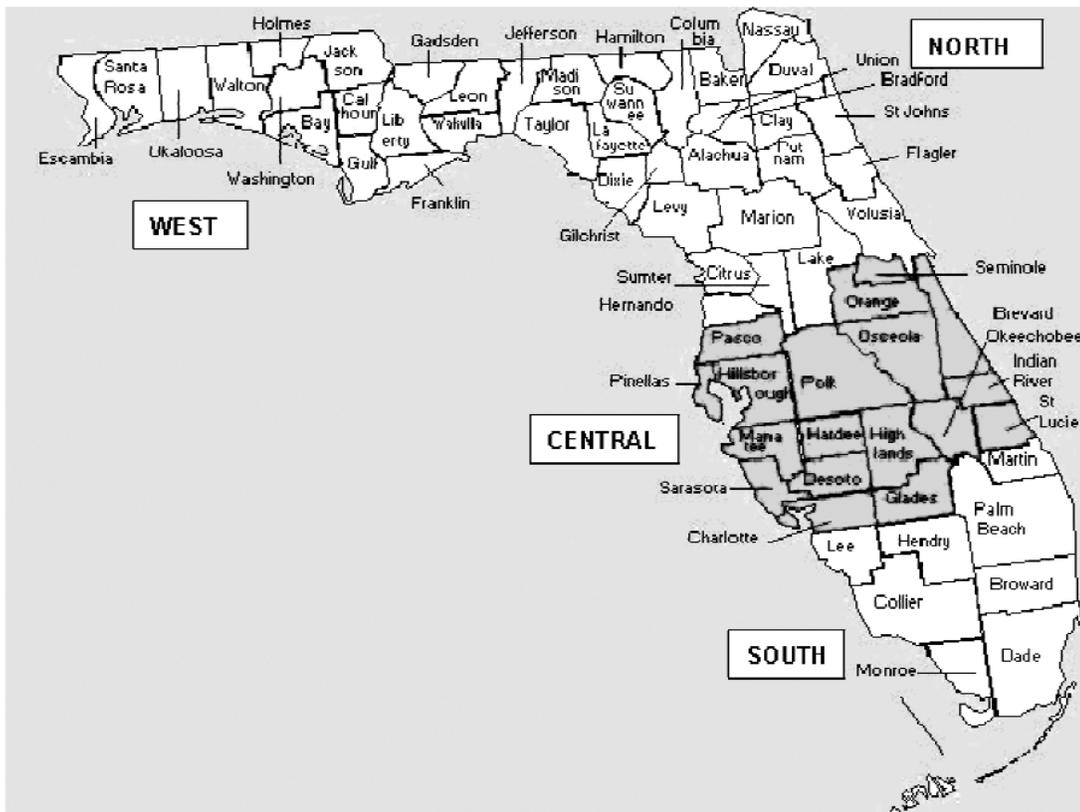


Figure 2. Geographical Locations in Florida



There appears to be an adequate number of licensed dentists in Florida to meet the present level of demand for dental services; however, there are not enough practitioners willing to provide care to people with developmental disabilities.^{16,19,22}

Legislators who passed laws mandating deinstitutionalization and normalization assumed that medical and dental services would be available in the private sector.⁸ No one intended for the move to the community to result in the deterioration of an individual's health, specifically, oral health. However, that is exactly what has been and is happening to some citizens who cannot access comprehensive oral care in their communities.²³ It appears, for the most part, that the community-based oral health care system is not providing the services needed by many people with developmental disabilities. This lack of comprehensive oral health care inevitably results in poor oral health, which affects the person's general health and well-being.

• What are the consequences of poor oral health?

A continuum of quality health care is one of the cornerstones that enables people who have developmental disabilities to lead productive, independent lives as “included” members of the community. For them, health care is not just a medical issue, it is an issue of maintaining or improving functional capacity as well. These individuals often experience serious long-term medical conditions requiring regular visits with specialists. They also require a delivery system that provides access to a full range of therapy and health services, not only to improve their health and well-being, but to prevent regression of their existing conditions.

The Surgeon General's Report on Oral Health in America¹⁷ states that oral health is a key component of general health and well being. You cannot have good health without good oral health. For the individual whose physical and mental functioning is impaired by a chronic, disabling condition, the consequences of poor oral health create additional barriers that prevent them from achieving optimum levels of health, well-being and functioning. The Surgeon General of the United States, Dr. David Satcher, said “. . .those who suffer the worst oral health include poor Americans, especially children and the elderly. Members of racial and ethnic groups also experience a disproportionate level of oral health problems. And, those with disabilities and complex health conditions are at greater risk for oral diseases that, in turn, further complicate their health.”

The consequences of poor oral health can affect a person's appearance, alter speech, and adversely affect mastication and other functions. Oral diseases can also have a detrimental affect on self-esteem, social interaction, education, career achievement and emotional state. Clearly, poor oral health can decrease a person's quality of life.

• What actions have been taken at federal, state and local levels to ensure access to care?

Inadequate access to comprehensive oral health services for children and adults with disabilities has been a concern to legislators, educators and agencies that advocate for, or are responsible for obtaining health care services for this population. What actions have been taken?

Most notably, the Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities. They must be provided with the same services as people who are not disabled. The Department of Justice has the responsibility for enforcing this law.

Although it faces many challenges, the Florida Developmental Disabilities Council continuously strives statewide to help people of all ages who have developmental disabilities to receive comprehensive medical and oral health care.

In the academic arena, the Florida Dental Association, the Nova Southeastern University College of Dental Medicine and the University of Florida College of Dentistry have each presented a variety of seminars and lectures and at least one teleconference aimed at informing community practitioners about the oral health needs of people with developmental disabilities and encouraging them to become involved in providing care. The Department of Pediatric Dentistry at the University of Florida offers an on-line educational course titled “Oral Health Care for Persons with Disabilities” at no charge to practitioners and professional students interested in treating people with disabilities.²⁴ The number of dentists who have decided to become service providers as a result of these educational efforts alone is undetermined. However, many practitioners have been made aware of the need for services, thus laying the groundwork for further actions, as recommended in this report.

There has been activity at the local level as well. For example, while most states prohibit non-residents of a DSI from receiving dental care at the state facility, Florida, Georgia and several other states have implemented a variety of local programs that do permit people residing in the community to access oral health services at the state institutions. These outreach programs are not uniform in nature. For example, since 1994, residents of the eleven counties that comprise District III of Florida’s Department of Children and Families have been able to obtain comprehensive oral care at Tacachale, a DSI in Gainesville, Florida. The Tacachale Outreach Program resulted from a local partnership between the University of Florida College of Dentistry and the Superintendent of Tacachale. In addition, there is a small number of private practitioners who are sensitive to the needs of people with disabilities and do provide comprehensive care to this population. Since reimbursement is inadequate considering the time, effort, expertise and staffing requirements, this amounts to a pro bono effort by these concerned practitioners. Unfortunately, these local efforts are limited in scope and do not solve the problem of inadequate access.

• What does the future look like?

For the foreseeable future, the trend to normalize and deinstitutionalize people with developmental disabilities and support them in home-like community residential settings will continue. In addition, health care for this population is continuously improving. Already, many of the conditions that were once acute and fatal have become chronic and manageable problems. As a result, these individuals have continued to grow in number and seek care from private practitioners. Therefore, there is an increasing need for dentists and other oral health care professionals who are able to identify and treat patients with systemic diseases, compromising conditions and disabilities that have an impact on, and can be impacted by, oral treatment. In conclusion, increasing numbers of individuals will require oral health care and general health care that is coordinated with their systemic and disabling conditions.

Why is there a lack of access to comprehensive oral health care? The following section explores specific problems that result in barriers to care experienced by people with developmental disabilities.

What are the Barriers to Access?

People with developmental disabilities, their parents, their group-home operators and their support coordinators face a number of obstacles when attempting to obtain comprehensive dental care for this special population.¹⁹ Before we can formulate appropriate strategies that will facilitate access to care, we must identify and understand the causes of these barriers

- **Reimbursement for services**

Reimbursement issues are important reasons why dentists opt not to treat persons with disabilities. The perception in the dental profession is that one cannot make a living treating persons with disabilities. Each source of funding presents a unique set of issues that exacerbates the problem.

Public funding levels are generally lower than most dental insurance coverage, with even more exclusions and limitations. Medicaid reimbursement fees are inadequate, attracting less than 15 percent of Florida dentists to enroll as providers. The program does not cover any dental care for persons over the age of 21, except for a limited extraction and denture service. Basic maintenance dental care and emergency care are not covered.

The Medicaid Waiver program covers qualified patients on a fee-for-service basis regardless of age. There are only five qualifying disabilities: autism, cerebral palsy, mental retardation, spina bifida and Prader-Willi Syndrome. Most dentists are unaware of the waiver program and/or do not know one can be a Medicaid Waiver provider without becoming a Medicaid provider. The application is daunting, and the procedure for gaining case-by-case approval for specific treatment plans is cumbersome.

Medicare covers individuals who are totally disabled, but only for medical purposes. Dental care is not covered at all, except for tumors and trauma to the oral cavity, excluding the teeth. An amendment to the Medicare Act, passed in the waning days of the Johnson administration, under which a dentist could certify the necessity for Medicare Part A coverage of hospital-related expenses only, has never been implemented by HHS regulation during any administration from President Nixon to President Clinton.

Children's Medical Services (CMS) coverage is available only within the context of limited regional centers and only from enrolled CMS providers.

Private funding is limited by the resources of the patients or their families. This is often determined by the combination of socio-economic status and years of above-normal medical expenses.

Dental Insurance Plans are often inadequate for the needs of the developmentally disabled and too costly for the working disabled. According to *Oral Health in America, A Report of the Surgeon General*¹⁷, most Americans do not carry private dental insurance. Capitation programs do not come close to adequate compensation for the time commitments asked of the dental team. The insurance companies' interpretations of what are usual, customary and reasonable charges under fee-for-service indemnity contracts may often be acceptable for usual and customary, but generally reject the narratives that accompany claims justifying the reasonableness of fees charged for time consuming patients. While it may be reasonable to charge a higher fee for a time-consuming patient, the Americans with Disabilities Act makes it illegal to charge more than one's usual fee to a time-consuming, special needs patient.

Hospitals and Out-patient Surgery Centers will eventually be paid when certain dental patients are treated in those facilities. This small improvement legislated by the mandate that medical insurance policies cover hospitalization of disabled children for dental procedures is discussed under the section on possible solutions. To date, it has had little effect, since it “kicks in” only at policy renewal time. Additionally, anesthesiologists and oral surgeons may or may not be paid depending on the status of the individual institution.

There are few philanthropic foundations interested in funding dental care for anyone. Some, like The Grotto, “adopt” specific children and pay for private care. Yet, they are limited by the availability of practitioners and the need to contain costs in order to help as many children as possible.

Given the economic and other deterrents discussed, it will remain difficult to convince dentists to join the “battle,” unless Congress and the Florida legislature can provide some creative relief. Medicaid Waiver notwithstanding, those with disabilities, developmental and otherwise, will generally continue to find it difficult to access dental care. This paper has not addressed the population with acquired disabilities. Those victims of traumatic injury- and disease-induced disabilities share these same barriers to access and will benefit equally from the solutions suggested herein.

• Behavior Management issues

Society’s goal is to mainstream as many aspects of disabled peoples’ lives as possible including the delivery of oral health care. The reality is that in most mainstream dental practices, the disabled are the most difficult patients to treat. Success depends on the application of behavior management techniques based on the doctor’s knowledge, care, skill and judgment, which require additional units of time beyond that required to deliver the same treatment to a patient without a developmental disability. Several approaches and modalities are available to control behavior. Each presents one or more hurdles to overcome.

Desensitization programs for fearful patients, including hypnosis, require one-on-one training time with the therapist who might not be the treating dentist, but whose time and efforts must be compensated. Voice control must be learned by interested dental personnel.

Sedation is available in several modalities. Sedation protocols require training beyond what most general dentists receive during their predoctoral educations. Because establishing and maintaining an intravenous line is often difficult when providing care to individuals with mental retardation and small children who are resistant, oral sedation, generally given as a pill or syrup, is particularly useful. However, the depth of sedation can be difficult to titrate with oral medications. Deep sedation and pediatric sedation, as defined by the Florida Board of Dentistry, require additional postdoctoral training and permitting. Parenteral (intravenous) sedation is generally not available in private dental offices. It requires additional training for all members of the dental team, a Board of Dentistry permit, specialized equipment and supplies and additional time, all of which increase costs beyond what is generally available for reimbursement.

General anesthesia is generally available only in hospitals and same-day surgery centers. Other than oral and maxillofacial surgeons, very few Florida dentists offer general anesthesia in a private dental office to persons with disabilities. That makes access difficult, irrespective of increased costs.^{25,26}

Patient immobilization and positioning techniques beyond what general dentists usually learn are available to assist in making dental treatment possible; however, there are liability and consent issues to

consider. Professional liability concerns are frequent deterrents to becoming involved in treating persons with disabilities. When a general dentist decides, after acquiring the necessary training, to offer parenteral intravenous sedation in his/her practice, the professional liability insurance premium doubles before the first patient arrives. Providing care under general anesthesia causes another doubling of the liability premiums. In addition an extra year of residency training, equipment, staffing, permit fees are required. Most dentists are unwilling to assume those financial burdens in the face of so much patient funding uncertainty.

Finally, dentists have been trained to perform intraoral procedures and use dental materials that require a high degree of precision and exacting techniques. Furthermore, dentists have been trained to provide comprehensive and ideal dental care to every patient (usually limited only by the patient's resources). When treating the resistant patient, the practitioner may only be able to provide limited or less than ideal care. This can be frustrating for the dentist and act as another disincentive to participate. Overcoming the effects of the dichotomy is an educational problem.

• Consent for treatment

In our present litigious society, more and more dentists have become aware of the need for a legally sufficient consent.²⁷ Informed consent and guardianship issues are a constant stumbling block in the practices of those who are willing and able to provide care. For example, many parents are not aware that once their child becomes 18 years of age, they are no longer the child's legal guardian and do not have the legal right to sign medical consent forms, even though they have been caring for their children's daily needs for eighteen years. In addition, the process of becoming the legal guardian for their own child can cost several thousand dollars. Hospital risk managers often cause last-minute cancellation of scheduled treatment over this issue. Moreover, Support Coordinators and other caretakers often make appointments for dental services and indicate that the patient is competent to provide consent for treatment. However, when the patient presents for treatment, it quickly becomes obvious to the dental staff that the individual is clearly incapable of providing expressed and informed consent. The dentist is placed in the position of explaining the law and the need to obtain a court-appointed guardian for the person before any dental care can be provided.

• Age Factor

Focusing on health care for adults as opposed to health care for children has become more important as modern medicine has increased the life expectancy of children with developmental disabilities. By definition, the practice of pediatric dentistry includes treatment of the disabled who, decades ago, often did not live to become adults. Today many pediatric practices are reluctant to treat a 40 year old patient who has cerebral palsy. They may feel ill equipped to manage the complex restorative and periodontal needs of such patients. This problem has been exacerbated in recent years because the postdoctoral pediatric dentistry training programs have been shifting the focus of their curricula more and more toward the youngest patients. The transition from child to adult is often blurred and made difficult by the perceptions of the public, including the dental team, as well as by the physical, mental and emotional problems of the patient.

• Medical Conditions

Associated medical conditions impacting the provision of dental care are almost as numerous as the table of contents of a pathology textbook. Persons with developmental disabilities suffer all the infirmities found in the non-disabled population, and some at increased rates of incidence. These unfortunate combinations add another layer of difficulty to finding access to dental treatment.

• Equipment

Special equipment requirements can add considerably to the high cost of building and equipping a dental office. Providing the special anesthesia techniques already noted requires the purchase of some or all of the following: an anesthesia machine, a pulse oximeter, a carbon dioxide monitor, a blood pressure monitor, a heart monitor (EKG), a defibrillator, a foot operated suction pump (in case of a power failure) and fail-safe lighting (if there are no windows in the office suite). Making a facility “accessible,” as required by the Americans with Disabilities Act, usually means wheelchair accessible. The advanced anesthesia techniques impose additional requirements, e.g. not being in a building where an overly small elevator prevents access by emergency medical technicians with a gurney (stretcher on wheels) in the event of an emergency. Like the increases in liability insurance premiums, the additional thousands of dollars required to meet these requirements is a severe deterrent.

• Scheduling issues

Time allocated to each person served is critical. Dental practices now frequently have overhead expenses at or near 60% of gross receipts. One can only see a finite number of patients in a given day. Any patient whose treatment extends the time normally allotted for that procedure in that practice cuts deeply into the 40% margin. Spending 90 minutes to deliver a 60 minute procedure costs three quarters of the provider’s net income. (Overhead jumps 50%, from 60% to 90%, while profit margins decrease 75% from 40% to 10%) That is a major deterrent to accessibility when patients and insurance companies resist appropriate fee increases and the Americans with Disabilities Act does not permit such fee increases.

Dentists in this situation have two choices. They avoid this patient population or they decide there is a moral obligation to serve them. So, they devote several hours a week to the people with disabilities and ignore the losses incurred. It is charitable; however, too often the patients tell others in their support groups about the wonderful dentist whose appointment book is soon overloaded. The dentist feels forced to beat an economic retreat. Making it illegal to charge a disabled patient a different fee from that charged to others created this unintended consequence, an economic disincentive, which must be resolved by Congress while we work to improve the other aspects of access to oral health care.

• Training needs

Training issues include the need to improve the pre- and postdoctoral curricula to include more and better training in these areas, the need to fund more general practice postgraduate residency programs in hospitals and dental colleges and the need to attract more young practitioners into academic careers to staff and facilitate these increased training programs. While the public is generally aware of how rapidly the over age 85 segment of the population is growing, the public is woefully unaware of how rapidly the numbers of persons with developmental disabilities is also growing. The shortage of dentists in this area of practice worsens every year.

• Specialty Services

For reasons explained above, treatment by specialists (orthodontists, oral surgeons, periodontists and endodontists) is generally not available to this population.¹⁶ However, some oral and maxillofacial surgeons are involved in the surgical correction of craniofacial anomalies and the provision of general anesthesia, and some orthodontists are involved in the correction of cleft palate and other craniofacial anomalies.

Potential Solutions

National data clearly indicates that oral health disparities exist in individuals with developmental disabilities.^{28,30,35,37,41,45} Effective solutions to provide comprehensive and quality oral health services to these individuals are needed. While the oral health literature has documented the problems that people with developmentally disabilities face in obtaining quality oral health care, there are few innovative solutions that have been proposed or implemented.

• Private Sector Solutions

As deinstitutionalization of the state developmental services institutions began, the large majority of all health care was considered to be the responsibility of the private sector.⁴⁴ Generally, the private sector has not succeeded in providing the comprehensive care required by many of the more severely affected individuals.^{37,44} Dentistry has experienced particular difficulty in providing access to quality care. Several authors have identified the primary reasons for inadequate oral health care in this population.^{41,44} These include poor reimbursement, increased time for treatment, difficulty in behavior management, difficulty in identifying sedation and general anesthesia facilities, disruption of the private office environment, lack of adequate educational training and experiences and difficulties in obtaining informed consent.

Interestingly, when dentists have been surveyed, they have generally reported a willingness to provide services to individuals with developmentally disabilities.^{39,40} While the majority of people with developmentally disabilities are treatable in the typical private office, the severely disabled offer a more difficult challenge.³⁷ Pediatric dentists are often able to provide services to the significantly disabled young patient in a private office, but once adolescence is reached very few primary care providers are equipped to manage these individuals.^{31,42}

The quality of care provided for people with developmentally disabilities by the private sector has been investigated. While many dentists provide exceptional care for these clients, others may cut corners and provide services at less than the standard of care.⁴¹ One study that evaluated a group of Special Olympics participants indicated that a high level of active disease was present even in patients who reported histories of routine dental care.²⁸ This finding may be associated with the intrinsic difficulty in providing highly technical oral health services to a population of marginally cooperative or uncooperative individuals.

What role does the private sector have in the maintenance of oral health for individuals with developmentally disabilities? For any health program to be successful, accessible primary care must be the cornerstone. Prevention programs and basic services must be available in local communities. In order to accomplish this goal, the pre-doctoral education of oral health care professionals must be enhanced.²⁹ Continuing education for primary oral health care providers must be available to ensure adequate knowledge for existing providers. Additionally, facilities for the individual who is severely and profoundly disabled must be provided outside of the private office environment.^{32,33} The provision of these facilities is critical in providing the referral support necessary for the dentists that accept people with developmentally disabilities into their practices.

• Governmental, Educational, and Institutional Solutions

Nordic nations have long sought answers to the problems of funding and access to oral health services for individuals with disabilities. While comprehensive oral health service plans have been implemented in these nations, the problem of access to dental care for the disabled has not been resolved. In response to this problem, Norway and Sweden have developed two specialized facilities called Odontological Competency Centers. These centers were developed to provide services to people with developmental disabilities who required highly specialized oral health diagnosis and treatment.³⁸ They have been successful in providing resources for difficult treatments, as well as valuable teaching and research environments.

The United Kingdom has recently implemented a model for regional dental treatment centers designed to provide tertiary oral health services to disabled individuals.⁴⁶ General practitioners provide primary care, while the Community Dental Service provides oral services unavailable in a private setting.

North American organizations have developed several models that address oral health care for the developmentally disabled. A San Francisco program developed in the early 70's was the first to utilize community-based primary care and specialized institutional care for the developmentally disabled.⁴³ It emphasized not only patient service, but also education of oral health care providers as a key component of the regional center concept. A comprehensive regional health care center for the developmentally disabled was developed in New Jersey in the mid 80's.⁴⁴ Dentistry was included in this multi-disciplinary center. Since many of the dental clients experienced multiple associated health problems, this center was able to provide an exceptionally high level of oral health care. A dental school-based program at SUNY Stony Brook was initiated in the early 80's and provides hospital care for the developmentally disabled.^{34,40} Its key providers were general practice residents of the dental college. These residents not only provided extensive care during their residency but also remained active providers of oral health services to the developmentally disabled following completion of their training. The University of the Pacific School of Dentistry recently reported the development of a dental school-based program which developed a community-based primary care network, offering referral for hospital treatment of complex developmentally disabled patients.⁹ Massachusetts has a longstanding program in cooperation with Tufts University School of Dental Medicine that provides primary care at 11 regional locations and utilizes a central facility to provide services requiring sedation and general anesthesia.⁴⁷ Several states have adopted mobile dental van programs to enhance primary care to those people with developmental disabilities in rural areas.³⁷ These programs provide access to patients but often fail to provide the complex oral health services needed by this patient population.

Several states have developed programs that provide outpatient dental services to non-institutionalized developmentally disabled patients at institutional facilities. These facilities often have existing dental clinics and staff who are experts in providing oral health services to persons with developmental disabilities.³⁷ While utilization of these facilities may be effective and practical, for some people there is a sense of stigma associated with the return of these individuals to the institutional environment for care, even out-patient visits.

Recommendations

People with developmental disabilities, their parents, siblings, foster parents, group-home operators and support coordinators want access to comprehensive oral health care for this special population. They do not want to experience the consequences of poor oral health due to a lack of access to care. They do not desire to travel hundreds miles roundtrip for each appointment to obtain care. Just like everyone else, they want to obtain primary dental care in their local communities from their family dentists.

Their desires are reasonable and understandable. Moreover, they are consistent with the goals of the United States Congress, as delineated in the Americans with Disabilities Act of 1990. The act prohibits health care professionals from discriminating against persons with disabilities. Medical and dental practitioners are required to provide services to all patients, consistent with their medical/dental needs and irrespective of their disabilities.⁴⁸ The act promotes inclusion, accommodation, mainstreaming and normalization.

These are the goals and desires of the U.S. Surgeon General's office¹⁷, the U.S. Department of Health and Human Services⁴⁹, the Academy of Dentistry for Persons with Disabilities and many other advocacy organizations.

The recommendations that follow are designed to establish and maintain a comprehensive statewide oral health care delivery system for citizens with developmental disabilities that is consistent with the aforementioned desires and goals. During the process of developing our recommendations, our task force elicited input from a diverse group of knowledgeable and experienced individuals, including parents, advocates, academicians, leaders of professional organizations and state agencies who have attempted to solve oral health care issues for people with developmental disabilities. We investigated strategies implemented throughout the United States that have been effective and those that have not produced the desired outcome.

Based upon our deliberations, an effective statewide program that meets the goals and desires outlined above should include each of the following elements:

- A community-based primary oral health care program in which quality services are provided by private practitioners.
- Regional educational and service centers which support community-based practitioners by:
- Providing adequate education and training in the provision of special care to people with developmental disabilities that would encourage and enable community dentists to provide care to this population in their private offices, i.e., replication of services provided at the support centers.
- Providing support to the community dentists by serving as a referral center with the ability to provide specialty care for more advanced or difficult cases.
- Facilitating the time-consuming process faced by practitioners who apply for Medicaid Waiver provider status.
- Reimbursement mechanisms that provide oral health care professionals with a fee level commensurate with the expertise, time and staffing needed to provide care to people with developmental disabilities, especially the more difficult cases.

- Incentives for hospitals and other health care professionals to participate in these important and costly treatment programs.

We, therefore, recommend the establishment of two Centers of Excellence: one at the University of Florida College of Dentistry (Gainesville) and one at the Nova Southeastern University College of Dental Medicine (Ft. Lauderdale). These Centers of Excellence will provide treatment for the most complex patients and the educational experiences for dental students, hygiene students and dental assisting students necessary to train the next generation of oral health care professionals who will be providing primary care to people with developmental disabilities. The Centers will also conduct continuing education programs necessary to train community practitioners in the provision of care for these individuals, so that these local providers can offer the same level of care to the individuals residing in their communities. The access problem will not be solved until a significant number of dental professionals have been adequately trained to provide the needed care.⁵⁰

Additionally, we recommend the establishment of five Regional Centers for the provision of care for this special population. We believe the most appropriate locations for the Regional Centers are Pensacola, Jacksonville, Orlando, Tampa and Miami. The focus of the Regional Centers would be to support the community practitioners and provide care to individuals who are more difficult to treat. They should be affiliated with hospitals that have facilities for sedation and general anesthesia. They will also provide continuing education necessary to train community practitioners and provide training to dental assisting and dental hygiene students from schools in their regions.

For the Centers of Excellence and Regional Centers to meet their goals, funding for an experienced full-time dentist and at least two dental assistants should be provided. Funding for services provided in the hospital setting should be included. Without the multidisciplinary support of the hospital staff, a quality oral health program for this population cannot be achieved.

The Centers will need ongoing support and direction. As the proposed program is being developed, each Center must work in partnership with organizations such as the Florida Department of Children and Families, the Association of Retarded Citizens, Florida's Voice on Mental Retardation, the Florida Dental Association and the Florida Developmental Disabilities Council to meet the needs of citizens with developmental disabilities. Finally, there should be an executive level position to oversee and coordinate the efforts of all seven Centers and possibly a Board of Directors, composed of a diverse group of individuals to ensure that the goals of the program are addressing the identified needs.

The Centers should use the Internet to improve accessibility to dental care for people with developmental disabilities and provide educational information to oral health professionals. For example, community practitioners who provide dental care to people with special needs should be listed on the Center's web site indicating whether or not they are Medicaid Waiver providers, if they use conscious sedation, if they provide hospital dental services and if they provide mobile dental services.

Perhaps the major barrier to access is the current financial disincentive involved in treating people with developmental disabilities. Community practitioners must be reimbursed at levels appropriate for the time, effort, expertise and staffing required to provide care for this special population. Once the community dentists are trained and have gained the skills needed to provide primary care to the residents of their communities, there will still be no incentive to do so, unless there is meaningful reform of the current public and private reimbursement systems. Without the needed reforms, the proposed program will fail to obtain buy-in at the community level. The Centers, rather than community practitioners, would then become, by default, the primary providers of care for this special population.

- **Caveat**

Lack of access to oral health care for people with developmental disabilities is a long-standing problem. Miller wrote about this problem 36 years ago.⁵¹ This is not a quick-fix proposal. There is no instant solution. However, if fully implemented, these recommendations should result in an oral health care delivery system that is in harmony with the desires of Florida's citizens with developmental disabilities and the people who care for and support them. It must be understood that improving access to dental services entails more than educating more dentists or even offering a reasonable reimbursement system. Access involves complex interactions often requiring the attention of educators and social scientists, as well as health care professionals.²²

It must be recognized that it will take time to phase in all aspects of the proposed program. Most importantly, it will take time to encourage and train community dentists at Regional Centers so they will be willing and able to provide services in their communities. In addition, the Regional Centers must actively continue to motivate and support the community dentists and impart the sense that the practitioner is not alone in providing special patient care.

While the shortage of well-trained primary care providers will not be immediately alleviated, this recommendation offers a long-term solution. The educational experience gained in pre-doctoral training, residency programs and continuing education at the Centers of Excellence will position the community-based practitioners of the future to assist the next generation of special patients in attaining and maintaining an optimal level of health for their lifetime.

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Glossary:

Adaptive behavior: means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age, cultural group, and community.

Assisted living or supported living: means a category of individually determined services designed and coordinated in such a manner as to provide assistance to adult clients who require on-going support to live as independently as possible in their own homes, to be integrated into the community, and to participate in community life to the fullest extent possible.

Autism: means a pervasive, neurologically based developmental disability of extended duration which causes severe learning, communication, and behavior disorders with age of onset during infancy or childhood. Individuals with autism exhibit impairment in reciprocal social interaction, impairment in verbal and nonverbal communication and imaginative ability, and a restricted repertoire of activities and interests.

Cerebral palsy: means a group of disabling symptoms of extended duration which results from damage to the developing brain that may occur before, during, or after birth and that results in the loss or impairment of control over voluntary muscles. For the purposes of this definition, cerebral palsy does not include those symptoms or impairments resulting solely from a stroke.

Deinstitutionalization: means the management principle of moving residents of state institutions into community residential settings which are as close as possible to the norm and patterns of the mainstream of society. See “normalization.”

Developmental services institution: means a state-owned and state-operated facility, formerly known as a “Sunland Center,” providing for the care, habilitation, and rehabilitation of clients.

Epilepsy: means a chronic brain disorder of various causes which is characterized by recurrent seizures due to excessive discharge of cerebral neurons. When found concurrently with retardation, autism, or cerebral palsy, epilepsy is considered a secondary disability for which the client is eligible to receive services to ameliorate this condition according to the provisions of this chapter.

Express and informed consent: means consent voluntarily given in writing with sufficient knowledge and comprehension of the subject matter involved to enable the person giving consent to make an understanding and enlightened decision without any element of force, fraud, deceit, duress, or other form of constraint or coercion.

Foster care facility or Foster home: means a residential facility which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. The capacity of such a facility shall not be more than three residents.

Guardian advocate: means a person appointed by the circuit court to represent a person with developmental disabilities in any proceedings brought pursuant to s. 393.12, and excludes the use of the same term as applied to a guardian advocate for mentally ill persons in chapter 394.

Group home facility: means a residential facility which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. The capacity of such a facility shall be at least four residents but not more than 15 residents.

Intermediate care facility for the developmentally disabled or ICF/DD: means a residential facility, state-owned or private, licensed in accordance with state law, and certified by the Federal Government pursuant to the Social Security Act, as a provider of Medicaid services to persons who are mentally retarded or who have related conditions. The capacity of such a facility shall not be more than 120 clients.

Mental retardation: means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the period from conception to age 18. "Significantly subaverage general intellectual functioning" means performance which is two or more standard deviations from the mean score on a standardized intelligence test specified in the rules of the department.

Normalization: means the principle of letting the client obtain an existence as close to the normal as possible, making available to the client patterns and conditions of everyday life which are as close as possible to the norm and patterns of the mainstream of society.

Prader-Willi syndrome: means an inherited condition typified by neonatal hypotonia with failure to thrive, hyperphagia or an excessive drive to eat which leads to obesity usually at 18 to 36 months of age, mild to moderate retardation, hypogonadism, short stature, mild facial dysmorphism, and a characteristic neurobehavior.

Spina bifida: means a developmental anomaly characterized by a defect in the boney encasement of the spinal cord.

Support coordinator: means a person who is designated by the Florida Department of Children and Families to assist individuals and families in identifying their desires, capacities, needs, and resources, as well as finding and gaining access to necessary services and support; coordinating the delivery of services and support; advocating on behalf of the individual and family; maintaining relevant records; and monitoring and evaluating the delivery of services and support to determine the extent to which they meet the needs and expectations identified by the individual, family, and others who participated in the development of the support plan. The support coordinator may be an employee of the Department or a private vendor.

