THE IMPACT we have upon the public’s dental and overall health has been covered in just about every type of dental publication. Prevention, alleviating pain, restoring proper form and function, and our participation in bringing about significant and beneficial esthetic changes in individual patients appear to be well appreciated. The demand for dental services is well documented, and our academic institutions are overflowing with dental colleagues from many different nations who are interested in acquiring skills that they will take home to their own countries.

What a wonderful time for the dental profession and for the public at large, whose members will be the ultimate beneficiaries of our efforts. Hidden somewhere, however, is an important part of our society that does not enjoy the benefits of modern dental care. This particular segment of our population, for many reasons, does not have access to quality dental care. And it is precisely this population that might very well be in the greatest need of even the most basic of dental services. Patients, such as ones with developmental disabilities, compel us to re-examine our fundamental philosophy toward dental health care.

This month, The Journal focuses upon the dental needs of special groups within our population. When we read these selected articles, we realize the complexity of the problem of providing dental health care to everyone, particularly special needs patients. We also get a glimpse into the efforts of our colleagues within and beyond the dental profession who continue to make progress in this particular area. They should be applauded as they inspire all of us to consider participating in the delivery of health care to patients with mental retardation and developmental disabilities.

Indeed, one of the greatest challenges the dental profession will face in the 21st century will be to facilitate smooth access for all who need and want dental care. So join us as we tackle this challenge in our continued pursuit of an inclusive dental health care environment. If just one dentist/reader of our Journal is motivated to seriously participate in the delivery of dental health care to special needs patients, then, our efforts will have been worthwhile.
Oral Surgeons Meet in New York

At Annual Meeting of New York State Society of Oral and Maxillofacial Surgeons, March 12 in New York City, outgoing President Victor Nannini, left, greets his successor, David Behrman.

OMS leaders at Annual Meeting include, front row, from left, Frank Sidoni, Steven Tunick, Lee Pollan, Arthur Elias, Andrea Behrman. Dr. Pollan is vice president, AAOMS. Others pictured are on NYSSOMS Board.

Among attendees at meeting at Weil-Cornell Presbyterian Medical Center were members of Fallon family. They are, from left, Brendan, Thomas, Michael Jr., Paul, Timothy, P. Casey.
Laser Treatment of Atypical Oral Pigmentation

A Case Report

Stuart Coleton, D.D.S.

Abstract

A 46-year-old female Caucasian patient presented with severe black pigmentation of the maxillary attached gingiva. The discoloration extended from tooth #2 to tooth #15 and was noted only on the buccal aspect of the arch. The patient reported that her gingival tissues appeared normal until age 22, at which time her first child was born. Cosmetic considerations prompted by this child’s impending marriage caused the patient to seek treatment. It was important to determine the cause of the pigmentation so that we would be reasonably assured that it would not recur. A CO2 laser was used to remove the pigmented tissue in such a manner that the postoperative period was both painless and rapid.

THE PATIENT, a 46-year-old Caucasian female, presented with severe pigmentation of the buccal surface of the maxillary attached gingiva as well as portions of the attached gingiva in the mandibular arch (Figure 1). This pigmentation was not present at birth and did not appear until after her first child was born 24 years ago. This child is now getting married, and the patient wants to improve her appearance before the wedding.

Etiology

The melanocyte is a specialized unicellular secretory gland found in the basal layer of the epithelium. The melanin pigment it produces can vary in color from light brown to black. The following substances must be present in the surrounding tissue for melanin production to occur: molecular oxygen; a tyrosine substrate; and tyrosine joined to the melanocyte. The melanocyte may remain dormant in the epithelium from birth. Both the enzyme tyrosinase and the amino acid tyrosine are always present in connective tissue. In the presence of copper ions, tyrosinase acts on the tyrosine to form melanin. During the third trimester of pregnancy, copper levels increase in the serum. If these levels are high enough, melanin is produced and pigmentation occurs.1

Treatment

The surgical site was anesthetized with two carpules of 2%
Lidocaine with 1:100,000 Epinephrine. The patient had been premedicated with 800 mg of ibuprofen, taken with food, one hour prior to the procedure. A CO₂ laser set at 4 watts continuous wave was used in a highly defocused mode to gently separate the epithelium from the underlying connective tissue by producing a laser peel. The epithelium is now ready for removal (Figure 2). Since the melanocyte, and therefore the pigmentation, are found in the basal layer of the epithelium, they were removed with the epithelial tissue. An antimicrobial mouthwash was prescribed.²

The patient’s first postoperative evaluation was in two weeks, at which time she reported that there had been no postoperative pain. The buccal mucosa appeared normal in color and tone and all traces of pigmentation had been removed (Figure 3).

REFERENCES
2. Chlorhexidine Gluconate 0.12%
A number of dental professionals from throughout the state were invited to serve on the task force, all in a volunteer capacity. Invitees included clinical dentists whose practices treat significant numbers of special needs patients, public health professionals, hospital dentists and dental school representatives. The inaugural meeting of the task force was held on February 10, 2003.

Many participants had been involved in quality initiatives in the past, and their experiences were not always positive. Accordingly, we were very sensitive to ensuring that our task force make timely and meaningful improvements in the quality of dental care for individuals with developmental disabilities.

From the outset, the group determined that it would “select only problems that are clinically important and practically solvable.” It was also established that some issues could be solved quickly, and others would take years to address. A brainstorming session was held to list issues affecting the quality of care for persons with disabilities in New York State. The issues were grouped into general categories, and committees were formed to start the process of developing solutions to address the issues.

The “plan, do, check, act” process was adapted as the methodology for implementing solutions, and committees began their work. The New York State OMRDD Task Force on Special Dentistry was born. Some of the task force’s accomplishments to date are listed here.

**Task Force on Special Dentistry Makes Meaningful Improvement**

*Gary Goldstein, D.D.S., M.B.A.*
Issues and Initial Solutions

Issue: Many patients with developmental disabilities who have complicated medical issues arrive at the dental office with an incomplete/unclear medical history.

Solution: A medical history form was developed by the Quality of Care Committee and placed on the OMRDD Web site (http://www.omr.state.ny.us/hp_dentistry_index.jsp). The form can be given to caregivers in advance to facilitate completion by an appropriate person prior to the first dental appointment.

Issue: Dentists may be unaware of the behavioral history of patients for past dental treatment, and there is no established mechanism to transmit that information.

Solution: A behavior management form was developed by the Quality of Care Committee and placed on the OMRDD Web site. The form can be given to caregivers in advance and filled out by an appropriate person prior to the first dental appointment.

Issue: Dental facilities operated by OMRDD were in need of modernization.

Solution: Reinvestment has been made to modernize facilities based upon a needs assessment by task force dentists. Plans for continuous reinvestment have been established via budgetary process.

Issue: Consumers and dentists often do not know where to obtain advice on dental issues that are specific to patients with developmental disabilities.

Solution: A list of task force members was placed on the OMRDD Web site. This listing serves as a resource for both providers and consumers.

Issue: Lack of data on access statewide to care and availability of sedation services for persons with disabilities.

Solution: The Access Committee completed the first statewide survey of dental facilities to measure access to care and availability of services. This will be an ongoing project with the goal of identifying areas of the state where lack of services may be acute.

Issue: Address areas in the state where there is a current crisis in access to dental care for individuals with developmental disabilities.

Solution: OMRDD staff has addressed these problems on a case-by-case basis by meeting with hospital administrators, arranging for increase in staffing or clinic capacity, or working to arrange contracts for services in an effort to solve local problems.

Issue: There is a lack of understanding in the dental community regarding rules surrounding Medicaid reimbursement, use of restraint, anesthesia and oral sedation.

Partial Solution: Presentations made to task force to clarify specific issues. Presenters included the following: Dr. Peter J. Ross, visiting lecturer, University at Albany, Management Science and Information Systems, School of Business; Dr. Joseph Guy, director, Bureau of Medical Review and Payment, New York State Department of Health; Dr. Ralph Epstein, chief, Division of Anesthesia and Pain Control, North Shore University Hospital Department of Dental Medicine, clinical assistant professor, Department of Hospital Dentistry and Anesthesiology, SUNY Stony Brook, rem, New York State State Board of Dentistry; Dr. Paul Glassman, president, Special Care Dentistry, associate dean for IT, director, Advanced General Dentistry Residency, co-director, Center for Oral Hygiene for People with Special Needs; and Dr. Anthony C. Caputo, state program coordinator-Arizona Region, Lutheran Medical Center AEGD Program, president-elect, American Society of Dental Anesthesiologists.

Also: Dr. Kenneth L. Reed, Board of Directors, American Dental Society of Anesthesiology, associate program coordinator-Arizona Region, Lutheran Medical Center AEGD Program; Dr. Sanford J. Fenton, professor and chair, Department of Pediatric Dentistry & Community Oral Health, University of Tennessee College of Dentistry; Eileen Zibell, attorney, OMRDD; and Patricia Johnson, attorney, New York State Commission on Quality of Care.

Issue: Caregivers need training in oral hygiene techniques that would be applicable to individuals with developmental disabilities.

Solution: The task force looked nationwide for best practices in the area of training caregivers on oral health for consumers. OMRDD purchased rights to the “Overcoming Obstacles” program developed by University of the Pacific and Dr. Paul Glassman, former president of Special Care Dentistry (SCD). SCD is a national organization that addresses the dental needs of various special needs population groups. Dr. Glassman was brought in by OMRDD to address the task force about this program and other issues related to care for consumers.

OMRDD is currently sponsoring statewide lectures using the “Overcoming Obstacles” program. For more information about this program, contact: Ms. Elaine Czerw, OMRDD Office of Internal Affairs; (518) 474-4376.

Issue: There is a need for ongoing caregiver and staff training on various topics in oral health.

Solution: OMRDD is sponsoring lectures on oral cancer screening for nurses. For more information about this program, please contact Ms. Czerw.

Issue: Perceived lack of training in dental schools and postgraduate dental residencies on care for persons with disabilities.

Solution: Task force members are available to lecture on care for persons with disabilities upon request. Also, the task force has been enlarged to include dental students and residents who have a particular interest in this area.

Issue: There has been a lack of communication and working relationship between OMRDD and the dental community.

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Solution: The mere existence of the task force has dramatically improved the working relationship between OMRDD and the dental community.

Issue: There is a need to educate dentists on special care dentistry and a need to spread the word to the dental community about the task force and its efforts.

Solution: This issue of The New York State Dental Journal is devoted to special care dentistry.

Conclusion
The dental needs of New York State citizens with developmental disabilities are great. The issues and potential solutions discussed at our meetings are just a beginning. The members of the OMRDD Task Force on Special Dentistry are volunteers who have given their time and energy to raise awareness regarding the difficulties persons with disabilities have finding dentists, receiving basic daily oral care, and improving the overall efficiency of the dental healthcare system that consumers find difficult to negotiate on a regular basis.

Use of the term “solutions” is not meant to imply that the problem is fixed, but, rather, that a group of dentists interested in a particular issue are suggesting to the dental community at large an initial or potential solution to a problem that, if embraced, would do much to improve the oral and general health of our most vulnerable citizens.

The accomplishments listed above are only solutions if all dentists treating persons with developmental disabilities know about and take advantage of the information provided. Every dentist, hygienist, dental student, caregiver and interested party is urged to contact a member of the task force for further information or assistance.

Looking for a special care dentist? Check out the OMRDD Special Care Dentistry Provider Directory at www.omr.state.ny.us.

REFERENCES

New York State Office of Mental Retardation and Developmental Disabilities
A Brief History and Timeline

Elaine Czerw, R.N.; Deborah Sturm Rausch

THE STATE OF NEW YORK coordinated its services for individuals with mental retardation through the Department of Mental Hygiene until April 1978, when the Office of Mental Retardation and Developmental Disabilities (OMRDD) was created by an act of the Legislature. The result of that action is a state agency that addresses the goals and interests of individuals with developmental disabilities and their families, provides services to those in need, and fosters local participation in a comprehensive system for New Yorkers with mental retardation and developmental disabilities.

OMRDD, through statute, has been given the responsibility for the prevention and early detection of mental retardation and developmental disabilities. In addition, OMRDD helped create the comprehensively planned care and treatment program for persons with developmental disabilities. The agency achieved its goals through the participation of families, nonprofit providers, advocates, local government representatives, state staff and the people it serves. As a result of this input, OMRDD fashioned a service system that is needs-focused and customer-driven. As specified in the legislation that brought about the creation of OMRDD, individuals with developmental disabilities receive services according to their individualized needs and as close to their homes and families as possible to enable them to realize their greatest potential.

The original legislation that created OMRDD as a separate office continues to serve as a guide today. Since its inception, the developmental disabilities service system in New York State has undergone radical changes. The agency’s early period focused on providing services for individuals, mainly through institutional settings, fitting the person into the service that was available, rather than the other way around. But, with the signing of the Willowbrook Consent Decree in 1975, a new era in service provision began, and OMRDD quickly moved to restructure its programs and services, moving from an institutionally-based to a community-based delivery system.

The early to mid-1980s were characterized by a commitment to de-institutionalization, and a new focus on the development of community programs, the encouragement of active treatment and the development of a professional field that would support services to persons with developmental disabilities.

The late 1980s and early 1990s saw a commitment to services based upon individual needs and to the enrichment and expansion of services in proportion to needs. Since the 1990s, the agency has increased its development of programs based upon individual needs, has recognized and established programs to address the needs of families caring for their family member with developmental disabilities at home, and has fostered the development of a strong self-advocacy system so that
persons with developmental disabilities can be in charge of their own destiny.

New York State is successful in serving individuals with mental retardation and developmental disabilities because of the partnerships that have been cultivated over the years among those who are involved in our efforts. Through participation in government, the state has created a system that treats people as individuals, where family is an integral part of life and where the focus is on inclusion in communities and employment.

Parents, family members, advocates, volunteers and those who receive services are involved in the continuing refinement of the system. They helped New York see and value each person as an individual, to appreciate and build upon the person’s abilities rather than his or her disabilities. Through this input, the system in New York State has been able to change and improve, to provide individuals with opportunities needed to achieve their goals and dreams.

Today, New York’s service system for people with developmental disabilities is one of hope, inclusion, opportunity and accomplishment.

Historic Highlights

1961: 27,000 persons with developmental disabilities living in institutions in New York State.
1968: OMRDD’s Institute for Basic Research in Developmental Disabilities (IBR) established.
1972: Television documentary, written and narrated by TV news journalist Geraldo Rivera, reveals deplorable living conditions at New York’s Willowbrook State School.
1972: Parents of 5,000 persons living at Willowbrook State School file suit in federal court over inhumane living conditions at the facility.
1972: First community residence for persons with developmental disabilities opens in New York State.
1975: Willowbrook Consent Decree signed. New York State commits itself to a program of improving community placement for Willowbrook class clients. Shortly thereafter, then-Governor Hugh Carey extends similar benefits to all persons served by OMRDD system.
1987: Willowbrook Developmental Center “officially and forever closed.”

December 1988: Approximately 16,000 persons living in community residences; about 15,000 families receiving Family Support Services; fewer than 9,240 persons living in developmental centers.

December 1988: Craig Developmental Center celebrates closure at new Dogwood Day Treatment Center in Dansvive, NY.

December 1988: Ceremony marks closure of Westchester Developmental Center.

November 1989: Rome Developmental Center closes. Open since May 1894, it had been one of first institutions in the United States to care for persons with developmental disabilities.

July 1991: Newark Developmental Center, once home to more than 4,000 persons with developmental disabilities, officially closes its doors.

August 1991: HCFA approves New York’s application for HCBS Waiver to allow persons to receive certain Medicaid-funded services while living in the community. The waiver would subsequently become a central component of the Individualized Service Plan, case management and other aspects of person-centered planning.

September 1991: Self-Advocacy Association holds first statewide seminar representing the coming of age of growing consumer empowerment movement in New York State.

December 1991: Manhattan Developmental Center, one of the first facilities opened to ease Willowbrook overcrowding, closes its doors.


December 1992: Bronx Developmental Center closes.

April 1993: IN Adam Developmental Center ceases operations.

June 1993: Long Island Developmental Center closes.

July 1993: The Center for Intensive Treatment opens at the Sun Mount Developmental Disabilities Services Office in Tupper Lake to provide specialized treatment services for individuals with developmental disabilities who have intensive needs.

December 1993: Developmental Center census 4,730. Just under 27,000 persons living in community residences, nearly 34,500 receiving Family Support Services, almost 46,000 in day services programs, and over 3,450 enrolled in HCSS Waiver.


December 1995: Approximately 65,000 individuals with developmental disabilities received support and/or services from OMRDD.


June 1998: Syracuse Developmental Center, one of the oldest facilities of its kind in North America, closes.

July 1998: There are nearly 31,900 persons living in the community—more than 56,600 receiving day services, about 51,650 receiving Family Support Services. Developmental Center census just over 2,100 residents. More than 30,000 enrolled in HCBS. Nearly 109,550 consumers served.

August 1998: Governor George E. Pataki announces “NYS-CARES” (NYS Creating Alternatives in Residential Environments and Services), a five-year plan to virtually eliminate the waiting
list for out-of-home residential services for people with mental retardation and developmental disabilities.

**June 1999:** Governor Pataki signs Chapter 86 of the laws of 1999, changing the name of the Letchworth Village Developmental Disabilities Services Office (DDSO) to Hudson Valley DDSO.

**December 1999:** The Parent to Parent Program is launched in New York State.

**October 2000:** The United States Department of Health and Human Services, Health Care Financing Agency (HCFA) declares that “openness and partnership characterize New York’s services” and that “advocates and family members... expressed high levels of satisfaction” with OMRDD’s services.

**April 2002:** Governor Pataki opens state-of-the-art Valley Ridge Center for Intensive Treatment (CIT) in Norwich. Second of two specially designed facilities in New York State, it will serve 60 individuals with developmental disabilities who require specialized intensive treatment services.

**September 2002:** Governor Pataki signs into law Health Care Decisions Act for Persons with Mental Retardation, which allows for court-appointed guardians of persons with mental retardation to “withhold or withdraw life-sustaining treatment” to alleviate extraordinary suffering when there is no hope of recovery for the individual.

**February 2003:** Task Force on Special Dentistry is established under auspices of OMRDD to assure better oral health of New Yorkers who have mental retardation and developmental disabilities. Members are dentists from throughout the state and professional as well as clinical staff with the goal of sharing critical information, problem solving, and developing creative methods for addressing issues related to dental treatment of special needs patients.

**January 2004:** OMRDD implements New York State-Options for People through Services (NYS OPTS). This unique initiative uses organized health care approach to promote increased choice and greater individualization of services and to expand and create additional opportunities through unique and flexible funding methodology.

**August 2004:** Governor Pataki signs Chapter 353 of 2004, which essentially codified the NYS-CARES initiative into law, assuring that this highly successful plan will continue. Adds language to §13.01 of the Mental Hygiene Law of New York, and states, “In recognition of the needs of these families for such assurance and peace of mind the legislature directs that, within annual amounts made available by appropriation, the NYS-CARES initiative shall continue to add in-home, residential and day service and support capacity over the next ten years in order to make the promise of timely, appropriate, and integrated community-based care a reality for all New Yorkers at their time of need.”
Providing Dental Care to Patients with Developmental Disabilities

AN INTRODUCTION FOR THE PRIVATE PRACTITIONER

Nancy Dougherty, D.M.D., D.A.A.P.D., D.A.B.S.C.D.; Roderick MacRae, D.D.S.

Abstract

During the past 20 to 25 years, in New York State, most individuals with developmental disabilities who had previously been housed in large institutions have been mainstreamed into community-based residences. This shift has created a need for dental services in the community. The article presented here provides information and tips to assist the general practitioner with integrating these patients into a private practice setting.

Beginning in the 1970s, New York State was in the forefront of the movement to deinstitutionalize individuals with developmental disabilities and integrate this population into community settings. As more and more consumers moved into neighborhoods throughout the state, community-based medical and dental services became a priority. The training of dental professionals to provide treatment to this population, however, has not kept pace with the demand.

Currently, the number of dentists engaged in institutional or public health dentistry is a minority, perhaps only 10 percent of the total in the state. It is to the vast pool of private practitioners to whom we look for assistance in meeting the monumental challenge of providing care for the developmentally disabled.

It has been estimated that as of 2001, there were almost 63,000 individuals with mental retardation or other developmental disabilities living in non-institutional settings in New York State. What, exactly, constitutes a developmental disability? The federal government has defined it as a severe, chronic disability of an individual that “is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in a substantial functional limitation in… major life activity.”

This definition encompasses a variety of disorders, including mental retardation, neuromuscular conditions such as cerebral palsy, seizure disorders, as well as behavioral diagnoses such as autism, Asperger’s Syndrome and Attention Deficit Hyperactivity Disorder. Because the definition covers a range of disabilities, it is difficult to generalize and provide a cookbook of techniques that will be effective for all special needs patients.

The modifications necessary in a practice to incorporate special needs patients should not be looked upon with dread or high anxiety. If we think about it, we make accommodations all the time for patients who present with medical concerns, varying levels of anxiety and other management concerns. We schedule appointments of optimal lengths at optimal times of the day to fit the needs of our patients. We may use inhalation analgesia or “headset analgesia.”
go a long way toward easing the backlog in making care available. For 25 years, Dr. MacRae's own practice has operated with a philosophy of broadening its base of service to include special needs patients. He has never looked back with regret.

Preparation and the First Visit
The length of time for the initial visit should be arranged to allow everyone to get to know each other. If you can anticipate beforehand the patient's response to the stimuli encountered during various dental procedures, it will help you to succeed in providing the best and most appropriate care for each patient.

The first visit should begin with a thorough medical and behavioral history. If the patient has a syndrome or a medical condition that you have not previously encountered, familiarize yourself with its features before proceeding with treatment. If the patient is accompanied by a family member, it is possible that this person may be very knowledgeable about the condition. Ask as many questions as necessary. There are also Web sites that have a vast array of information on almost every developmental or medical condition imaginable. Doing an advanced search on Google is probably one of the easiest ways to find useful sites.

In many instances, it may be necessary to consult with the patient's physician to obtain a complete list of medications and to ascertain the need for any special precautions prior to or during treatment.

It is always useful to inquire about the patient's prior dental experiences during the initial interview. Was the patient able to cooperate for all necessary procedures? Did the patient become physically resistant at any time? If the patient has adequate communication skills, he or she may be able to relate past experiences and articulate fears and anxieties. If the patient is not verbal, the

Modifications to accommodate special needs patients in dental practices are not much different from what is done to accommodate patients with medical and other management concerns.
allow for an easier integration into your practice. Even if in a community residence of 10 individuals, only five or six can be seen in a private office, an enormous amount of good will have been done. The other residents, whose behavior or medical management concerns are more involved, may require a higher level or more specialized mode of care. Maintaining a current list of clinics or hospitals in your geographic area that can provide more specialized care can be very helpful for caregivers, who often have a difficult time locating services for their more complicated residents.

The Appointment

Expectations for what can be accomplished in a visit may vary from what we are accustomed to delivering. If, in a 45- to 60-minute appointment for a new patient, we might expect to perform an oral exam and oral cancer check, X rays, periodontal probing and some amount of scaling and prophylaxis, then in the initial visit with a special needs patient, we may only accomplish an introduction, medical history review and exam. This timetable, however, can be expected to accelerate as all parties become more familiar with each other. Although it may never quite match the typical time frames of the practice, it can get very close.

In almost 25 years of treating special needs patients, we have never had a complaint from other patients about behaviors in the reception area. Indeed, the response from the community has been most favorable, recognizing the value of providing this kind of care. However, there are some areas of appointment management that should be discussed.

Morning is often the most convenient time for patients coming from community residences because of the shift schedule of the accompanying staff. Minimizing wait time is also helpful. There often tend to be fewer broken appointments from this group, since the agencies responsible for the care of special needs patients are under the scrutiny of state monitoring departments and are obligated to see that those for whom they are responsible receive necessary services, including dental.

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) has downloadable medical and behavioral history forms that address many issues of concern to practitioners treating people with developmental disabilities. These forms can be accessed on the OMRDD Web site at www.omr.state.ny.us. Click on the heading for OMRDD’s Task Force on Special Dentistry and scroll down to find the forms.

Prior to this, it would be helpful to review with the office staff the aims and expectations in embarking on this new area of care. Remember that generally, the patients who will be seen in the office are those who are higher functioning, who will probably be able to communicate, and whose social and communicative skills will

accompanying person (especially if this person is a parent) may be very helpful.

Often a parent or knowledgeable group home counselor will be able to supply information about specific sensitivities with which the patient has had previous problems (water spraying, loud noises, being in a reclining position, etc.). They may also be able to relate techniques that have been helpful in the past, such as allowing the patient to listen to music on headphones or proceeding with treatment slowly and explaining everything (tell-show-do). Remember, the patient is a person and should be addressed even if it is the accompanying person who is providing the history.

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In an ideal situation, intraoral X-rays should be taken as with any other patient. However, neuromuscular and anatomic situations may limit the number and kind of views that can be taken. A panoramic radiograph, while not necessarily ideal, can serve the purpose.

**Treatment Planning**

Treatment planning is a highly individual matter in the special needs population. It should be based on the patient’s ability to tolerate the needed treatment and how well the patient alone, or with the assistance of the caregiver, can maintain hygiene after treatment is rendered. Periodontal needs are often the most immediately pressing and most typical ongoing problem.

At the very least, we want to keep the patient free of pain and infection and do what can reasonably be done to improve function and enhance quality of life. This, however, is a minimum. If the patient’s circumstances allow it, a more involved treatment plan can be developed and delivered. Perhaps in the initial stages of the doctor-special needs patient relationship, and until all parties build trust and familiarity, the wiser path is traveled in small steps. This does not mean that pressing needs to address and treat potential pain and infection are ignored, but ambitious prosthetic treatment plans can be approached more cautiously. Building familiarity on a basis of consistency and continuity of care will result in the common sense that leads to sound clinical judgment about what the patient needs and will tolerate.

**Summary**

We should not think in terms of what can’t be done when making the decision to treat special needs patients, but approach it in more realistic and positive terms of what can and should be done. After all, special needs patients want the same thing all of our other patients want: comfortable, quality dental treatment from a caring provider in a non-threatening atmosphere.

**REFERENCES**

Abstract
Down syndrome is one of the most frequently encountered and easily recognizable of all developmental disabilities. Patients with Down syndrome exhibit mental retardation and often present with associated medical conditions, such as cardiac defects, immune deficiencies and musculoskeletal disorders. It is important for the dental practitioner to be familiar with the medical aspects of Down syndrome, as well as the potential behavioral issues. We present a brief review of Down syndrome for the dental provider and suggest that with a little knowledge and some patience, most private practitioners can easily accommodate these patients in their practice.

Down syndrome, also termed Trisomy 21, is the most common malformation syndrome, with an incidence of 1 out of 600 to 1 out of 1,000 live births. It is characterized by a generalized mental and growth deficiency, along with readily recognized craniofacial features (Figure 1). The frequency of occurrence increases with maternal age, and there is no racial, social, economic or gender correlation.
Compromised Immune Status

Compromised immune status is often seen in patients with Down syndrome. Increased susceptibility to bacterial and viral conditions, as well as acute leukemia, has been reported. Immunological alterations, such as decrease of circulating B cells, decrease of CD4+ cells and increased percentage of cells bearing markers associated with natural killer cell activity, are well established. This may help explain the higher incidence of chronic upper respiratory tract infections, pneumonia and periodontal disease seen in this population. While the exact etiology of the increased susceptibility to infection is uncertain, the dysfunctional and short-lived neutrophils have been postulated to contribute to impaired immunity.

The incidence of acute leukemia in patients with Down syndrome is approximately 1 in 200, which is 15-50-times higher than in the general population. Oral signs of leukemia include persistent lesions and spontaneous gingival bleeding. Therefore, frequent recalls and maintenance visits, every three to four months, should be scheduled to monitor periodontal and soft tissue status.

Approximately 5% of Down syndrome cases have an extra chromosome 21 (Trisomy 21), giving them 47 chromosomes instead of the normal 46. The remaining 95% have other chromosomal abnormalities, which include translocation (3%) and mosaicism (2%). In translocation, the extra chromosome is not free but is relocated onto another chromosome (13 or 15), and the count still remains 46 chromosomes. In mosaicism, some cells have 46 chromosomes and other cells have 47. Both these anomalies are mild, with almost normal intelligence.

With Down syndrome, there is a significant range in the degree of mental retardation. Some individuals may have an IQ above 69, but most are moderately to severely retarded with an IQ of 20-50. Individuals with Trisomy 21 often present with associated medical conditions. Congenital heart defects, immune and hematologic disorders, and musculoskeletal and nervous system anomalies are common. A consultation with the patient’s primary health care provider is recommended prior to commencing dental treatment.

Congenital Cardiac Anomalies

Approximately 40% of individuals with Down syndrome have some type of congenital cardiac defect. Atrioventricularis communis, ventricular septal defects (VSD), patent ductus arteriosis, atrial septal defects (ASD) and tetralogy of Fallot are the most commonly exhibited cardiac defects. All of these conditions can be surgically corrected, generally with a good prognosis.

The prevalence of mitral valve prolapse (MVP) is 5% to 15% higher in individuals with Down syndrome than in the general population. Consultation with the patient’s primary care provider or cardiologist is advisable. If antibiotic prophylaxis is indicated, the guidelines established by the American Heart Association should be followed.

Oral and Dental Anomalies

Individuals with Down syndrome may present with significant oral and dental anomalies. The main orofacial characteristic of Down syndrome is midfacial hypoplasia (Figures 2 & 3). This includes smaller and sometimes absent frontal and maxillary sinuses, narrowed nasal passages and nasal septum deviation. The midface hypoplasia also results in a relative Class III occlusal relationship
The most common dental anomalies exhibited in Down syndrome are variations in the number and morphology of teeth.

Tooth eruption may be delayed, may occur in an unusual order and can be two to three years behind a child’s “normal” eruption pattern. Over-retained primary teeth are common.1,4 There is a high incidence of impacted cuspids and bicuspids, and hypodontia is a frequent finding. Peg laterals, shovel-shaped incisors and taurodons are often exhibited (Figures 4-6).

**Conclusion**

Most patients with Down syndrome are easily accommodated in the general practitioner’s office with a few special considerations. As with any patient, a thorough medical history should be taken; issues of atlanto-axial instability and cardiac conditions must be investigated; and consultation with the patient's physician(s) may be indicated.

Understanding the patient’s cognitive abilities is of paramount importance. Standard behavior management techniques, such as tell-show-do, can be very useful in eliciting the patient’s cooperation.

A patient’s functional level, his/her ability to cooperate for home care, anatomical variations and occlusion issues should all be taken into consideration when formulating the treatment plan for a patient with Down syndrome.

**REFERENCES**

Providing Dental Care to Patients with Developmental Disabilities

MEDICAL/LEGAL ISSUES


Abstract

Dentists providing treatment to individuals with developmental disabilities are often faced with unique medical/legal issues. Obtaining informed consent when a patient does not have capacity can be an involved process. Issues regarding therapeutic aids used for immobilization during treatment may further complicate the situation.

Many adults with developmental disabilities live in community-based group residences rather than with their families. These residences are operated either by the state or voluntary agencies. All of these facilities are certified and subject to regulations promulgated by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD).

Obtaining Medical Information

In the case of a patient living in a group home, the dental practitioner will usually have little to no contact with the patient’s family members. Obtaining a medical history from a reliable historian may not be practical. However, group home residents will have an annual physical examination on record, as well as a list of current medications. This information should be available in the patient’s “Big Book,” a binder that contains guardian information, a record of past medical and dental visits, dietary restrictions, and behavioral and social information.

Most agencies will send the Big Book along with the patient for dental visits. In addition, patients usually will present with a consult sheet to be completed and returned by the dentist. If the Big Book is not available, and medical information is not provided on the consult sheet, a written request to the agency is an effective method for obtaining necessary information.

All group homes must have a nurse on staff who oversees the general medical care of the consumers. The nurse should be the primary contact in cases where additional medical information is required, especially if care must be coordinated with other medical specialists.

Consent

Informed consent is the process of communication in which a patient grants permission for a proposed treatment based upon a realistic understanding of the nature of the illness, description of the procedure, associated risks and benefits, and all treatment alternatives, including no treatment at all.

Many dentists in private practice do not have a formal consent form for general treatment. Patients presenting to the office for treatment fill out their insurance and medical history forms and then willingly submit for treatment. This is known as implied consent. If a person with capacity makes an appointment and presents for that appointment, that person’s consent for treatment is implied by his or her actions. Some commercially available medical history forms may also have a section for an explicit consent for treatment, but, by and large, in the
world of private practice, general dentistry is conducted under implied consent.

In New York State, people age 18 or older may give consent for dental treatment for themselves. For a minor child, a parent may give consent. Minors under 18 may consent on their own behalf if they are parents, are married or have been married, or are legally emancipated. A pregnant minor may give effective consent for medical, dental, health and hospital services relating to prenatal care regardless of age.¹

For patients who lack capacity to grant their own consent, an explicit consent for treatment, given by the legal guardian, is a more prudent choice. Many adult patients living in group residences fall into this category. Prior to treating, the patient consent must be obtained from the legal guardian. This should be documented with an original signature.

For adults living in facilities operated by or certified by OMRDD, the following people may grant consent in this order: legally appointed guardian; actively involved spouse; actively involved parent; actively involved adult child; actively involved adult sibling; actively involved family member; Community Advisory Board Representative (for patients who have one appointed by the state); Surrogate Decision Making Committee; Court of Competent Jurisdiction.² It should be noted that this differs somewhat from the Public Health Law in that siblings, grandparents and aunts or uncles are not included in the list hierarchy. Of course, any of these people may be the legally appointed guardian.

The Surrogate Decision Committee was established under Article 80 of the New York State Mental Hygiene Law.³ It allows for health care decisions to be made in a timely manner for an individual who does not have capacity and has no legal guardian. The committee is made up of panel members throughout different geographic regions in the state. Any panel convened for a hearing of a petition on behalf of a patient consists of members from the following groups:

- Physicians, nurses, psychologists or other health care professionals licensed by the state of New York (including dentists).
- Former patients, parents, spouses, adult children, siblings or advocates of mentally disabled persons.
- Attorneys admitted to the practice of law in New York State.
- Other persons with recognized expertise or demonstrated interest in care and treatment of mentally disabled persons.

The panel considers the following three questions:

1. Does the patient have capacity?
2. Is there an available and willing surrogate (to sign consent)?
3. Is the proposed treatment in the best interest of the patient?

The panel then renders a decision and may either grant consent for the procedure, or may request further information or testimony.

Most group homes are familiar with the process of getting consent and can be very helpful. You should inquire of the residence manager or house nurse who the patient’s legal guardian is. Consent forms can be sent with the patient’s escort to be signed at the residence by the guardian. It is useful to have your name and number on the consent so that the guardian may contact you with questions regarding the patient’s treatment.

For specific consents, that is, extraction, sedation, apicoectomy, biopsy, etc., it is wise to actually speak with the guardian either by phone or in person to be sure the process of informed consent is properly completed.

**Restraint**

The majority of patients with MR/DD are in the mild to moderate range.¹ However, patients with more severe disabilities may require therapeutic aids to facilitate treatment. Examples of such aids would be a papoose board, or Velcro straps for the wrists or legs. These devices do not meet the legal definition of a restraint.⁵ Their use is permitted under certain circumstances by OMRDD regulations.³ However, if you are considering using a papoose, you should first consult with the patient’s group home manager concerning the agency’s Human Rights Committee procedures for the use of any type of restraint.

The correct and safe use of restraint devices requires not only proper training, but also a certain comfort level on the part of the practitioner. A specific consent for use of the therapeutic device should be obtained from the patient’s legal guardian. In some instances, you may need agency as well as guardian consent prior to using any kind of restraint. Again, be sure to check with the individual’s agency.

The importance of classic behavior management techniques, such as tell-show-do, cannot be overemphasized. Any type of therapeutic device should be employed only after all other behavior management techniques have been exhausted. All patients should be treated with respect and dignity and given every opportunity to participate willingly in their dental care.

Optimal dental treatment in the least restrictive setting can often be achieved by actively engaging the people involved with the patient’s daily life. A careful behavioral history is important. (A behavioral assessment form can be downloaded at www.omr.state.ny.us.) Consultation with the patient’s guardian, direct care staff, residence manager or house nurse is recommended and can be extremely helpful in the successful treatment of the special needs dental patient.

The information in this article is current and true to the best of the authors’ knowledge; however, it should not be construed as legal advice. Practitioners should consult the Office of Mental Retardation & Developmental Disabilities Counsel’s Office, 44 Holland Ave., Albany, NY 12229, (518) 474-7700, for additional information and assistance.

**REFERENCES**

1. Public Health Law Article 25 Title 1 section 2504.
2. NYCRR Title 14 Part 633.11.
3. Chapter 27 Title E Article 80.
6. Part 633.16.
Effect of Preventive Dentistry Training Program for Caregivers in Community Facilities on Caregiver and Client Behavior and Client Oral Hygiene


Abstract
The influx of persons with developmental disabilities into community-based programs has required the development, expansion and improved integration of community-based services. The role of caregivers in these community settings has become pivotal. However, with regard to daily activities, oral hygiene is often a low priority. Few attempts have been made to study caregiver participation in oral disease prevention and practices. This study evaluated the effects of an indirect training program, where caregivers were trained but the ultimate effects were demonstrated in adult clients. In addition, these effects were demonstrated in community care settings.

A multiple baseline design, across three group homes, included 11 adult clients with developmental disabilities. This study evaluated the effects of training, instruction to use training and coaching on the presence of caregivers during oral hygiene sessions, the duration of toothbrushing and plaque scores of the clients. The results of this investigation demonstrated that there was an increase in caregiver presence and duration of brushing with a concurrent decrease in plaque scores.

Caregivers responding to social validation questionnaires believed that 8 out of 11 clients had increased skills. This study demonstrates that caregiver training, combined with specific instructions to use training information and coaching of caregivers, can have a positive impact on the oral health of individuals with developmental disabilities living in community settings.

STUDIES OF PERSONS with developmental disabilities living in community settings report that these individuals have significant unmet dental needs. Inadequate oral hygiene and a greater prevalence of periodontal disease are widespread problems among persons with developmental disabilities. The situation is even worse for people with disabilities living in community settings and in rural areas of the country. In addition, almost two-thirds of community-based residential facilities report having inadequate...
access to dental care. A study commissioned by the Special Olympics concluded that individuals with MR have poorer oral health, more untreated caries and a higher prevalence of gingivitis and other periodontal diseases than the general population.

As is widely understood, poor oral hygiene refers to inadequate removal or disruption of the microbial plaque; and poor plaque control can result in gingivitis, periodontitis and dental decay. To date, the most widely accepted, affordable and dependable method of plaque control is via mechanical cleaning using a toothbrush and other aids, such as floss, rubber tips and toothpicks. Even though chemical agents, such as fluoride, chlorhexidine and xylitol, have shown great promise in preventing dental disease, they are still considered as adjuncts to mechanical techniques.

Since the 1970s, as a result of educational, legal and social forces, there has been a significant movement of people with developmental disabilities from segregation inside institutions to integration and, now, inclusion, in the community. With the paradigm shift from institutional to community-based support for adults, the responsibility for proper oral hygiene care has transferred from employees of state institutions to group home staff. Among the obstacles that keep a deinstitutionalized person from maintaining good oral hygiene is the lack of consistent supervision of daily oral hygiene practices.

Even in community settings where caregivers receive hygiene training programs, the turnover of direct care staff is an impediment to effective, continuous oral hygiene care for clients. It has been shown that 65% of the staff said additional resources were needed to deal with staff turnover problems. Therefore, it is important, in terms of dental disease prevention, that easy-to-use training programs be made available to educate new employees in community-care settings.

The use of behavioral techniques to prevent dental disease has been studied primarily with non-disabled people, inside institutional settings or with children with disabilities in school-based programs. There is a dearth of studies about training programs in institutional settings or with children with disabilities in school-based programs. A previous study of the effect of a six-hour training session using these materials demonstrated a significant improvement in caregiver knowledge of dental and behavioral principles after the training program.

The primary purpose of this current investigation was to examine the effect of specific knowledge acquisition by licensed community care providers on their own and client behavior related to oral hygiene. It was anticipated that following training, caregivers would be present more often during oral hygiene sessions, the duration of client brushing would increase and client plaque scores would decrease. Additionally, it was the intention of the researchers to evaluate a training methodology that could be used to assess caregivers’ ability to apply knowledge about health promotion practices with adults in community settings.

**Methods**

**Subjects**

Eleven adult clients with developmental disabilities and 10 caregivers were selected to participate in the study. Client participants, whose preventive dentistry skills were monitored during the research investigation, met the following criteria:

1. They had at least eight upper and eight lower teeth. Their teeth had no large cavities, and the clients were not experiencing pain from any teeth.
2. Clients had moderate-to-poor toothbrushing skills.
3. Clients were able to tolerate visual inspection of their teeth.
4. Clients were able to learn new skills through systematic instruction (i.e., systematic prompting with reinforcement) and were not resistant to teacher directions.
5. Clients remained in study for at least five months.

Caregivers who participated in the study had good proficiency with English, were employed for the duration of the investigation and were interested in improving their knowledge of preventive dentistry. For participation in the training component of the study, caregivers received continuing education credits that partially fulfilled employment requirements. Informed consent documents were obtained for all participants.

**Setting**

Client participants lived in licensed community-based residential facilities (i.e., group homes) in Northern California. The study sites were located in three medium-sized cities (referred to here as City #1, City #2, City #3).

Three clients lived in a group home in City #1. There were three regular employees at the group home. Of these employees, two participated in the research investigation. Two clients lived in a group home in City #2. These clients were routinely assisted by two caregivers who participated in the study. Six clients lived in a group home in City #3. Six caregivers from this home participated in the study.

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the various dependent measures.

**Observational Measures:**
Four dependent measures were monitored throughout the investigation. Three of the target behaviors were obtained from videotape recordings of each toothbrushing session. One observational measure (i.e., plaque score) was obtained immediately following each toothbrushing session by the field observers. Data for participants living in the same home were pooled, and results represent a mean score per house for each dependent measure.

Toothbrushing sessions were videotaped and analyzed by an observer, who scored the toothbrushing sessions as described below. Two dental assistants and one dental hygienist were trained as field observers during two, three-hour sessions to insure correct camera angle and specific focus on caregiver and client interactions during the sessions. The observers reviewed training tapes and were briefed on the dependent measures of the study. They also received feedback about tape quality throughout this phase. Two additional observers were trained to score the videotapes and to gather reliability data.

**Caregiver Presence:**
Review of videotaped sessions included assessment of caregiver’s presence during the toothbrushing sessions. The videotape observer used a plus/minus recording system to indicate whether or not the caregiver was observed at any time during the taped session. A percentage score was calculated by totaling the number of sessions in which the caregiver was present during a given phase, dividing by the total number of taped sessions in the phase and multiplying by 100. It was expected that after training there would be an increase in the number of sessions in which the caregivers participated.

**Percentage of Tooth Surfaces Brushed:** The percentage of surfaces brushed was also calculated from observations of the video-tapes.

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**Experimental Procedures**

**Social Validation:** Social validation of clients’ abilities with regard to preventive oral hygiene was obtained prior to beginning baseline and after the study was completed. Caregivers and home managers completed questionnaires that focused upon their perceptions of clients’ aptitudes. They rated their responses to eight statements using a six-point scale with a range of responses from “not at all” to “definitely.” Statements included: “client has good oral hygiene”; “you enjoy working with this client during toothbrushing”; “teaching toothbrushing is easy”; and “client is benefiting from toothbrushing.” It was expected that ratings would increase by the end of the study. Additionally, one month following the conclusion of the investigation, caregivers were contacted by telephone and asked to respond to six open-ended questions pertaining to their perceptions of the training and research study.

**Design:** A multiple baseline design across three facilities was used to assess the effects of preventive dentistry training provided to the caregivers. A continuous graphed measurement of the data was maintained throughout the study. Trend analyses and phase means were used to evaluate the efficacy of the treatments across the various dependent measures.

**Table 1**

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tapes. To increase the accuracy of this dependent measure, observations focused on five specific areas of the mouth (i.e., right-inside, left-inside, right-outside, left-outside and front). Brushing of chewing surfaces was not counted. The percentage of surfaces brushed was calculated by adding the total number of the target surfaces brushed during an observation session, dividing by five (i.e., total target surface) and multiplying by 100. An increase in the percentage of tooth surfaces brushed was expected after training.

**Duration of Toothbrushing:** A toothbrushing task analysis data sheet was used to collect data from videotapes on the ability of the client and caregiver to complete various steps in the process of toothbrushing. The data sheet was developed from material taken directly from the caregiver training workbook. The duration of toothbrushing in seconds and percentage of tooth surfaces brushed were recorded on this standard data collection sheet by the videotape observer. Duration measures were obtained by using a standard stopwatch. The videotape observer started the stopwatch when the toothbrush touched the client's lips. The watch was stopped when the brush was removed from the client's mouth at any time during the session. The duration of brushing in seconds measured reflects the actual amount of time the toothbrush was in the client's mouth. An increase in the client's duration of toothbrushing was expected after training.

**Plaque Score:** A visual inspection of the client's teeth was conducted in the field after each toothbrushing session. This Simplified Oral Hygiene Index (OHI-S) was used to measure the amount of plaque and debris present on the client's teeth. Detailed instructions were provided in the field after each toothbrushing session. The Simplified Oral Hygiene Index (OHI-S) was used to measure the amount of plaque and debris present on the client's teeth. Detailed instructions were reviewed, and repeated practice sessions were conducted with field observers prior to its use. Scoring using the OHI-S involved rating the amount of debris observed on six standardized teeth (e.g., upper-left first molar). The observation involved moving a dental explorer from the incisal edge of each target tooth toward the gingival third to measure the extent of plaque and debris. A four-point scale was used to score the amount of plaque (i.e., no plaque, some debris—not more than one-third of the tooth surface; some debris—covering more than one-third; and debris covering more than two-thirds of the tooth surface). An average plaque score was calculated by adding the plaque scores and dividing by the number of teeth examined. It was expected that average plaque scores would decrease after the caregiver training sessions were conducted.

**Baseline:** During baseline, caregivers were not given any directions, information pertaining to the purpose of the research investigation, instructional strategies, proper oral hygiene techniques or other information directly related to the research project. Caregivers did not receive instruction about assisting clients during toothbrushing sessions, but were expected to be present in the home during scheduled observation sessions.

During the observation session, observers refrained from making any comments and remained as unobtrusive as possible. Observers arrived approximately 10 minutes early to set up video equipment in the bathroom area. Data for the duration brushing and caregiver presence were collected by videotaping the entire oral hygiene session. After the session, the field observer examined the client's mouth with a headlamp, mouth mirror and periodontal probe. Inspection data were recorded on a standard OHI-S form. The observers thanked the clients for their cooperation during the examination, but refrained from offering specific comments about the clients' performance during the toothbrushing session. Two observation sessions were conducted at each house each week throughout the baseline phase. Videotapes were mailed for scoring on a weekly basis.

**Training:** Caregivers received specific training in preventive dentistry and basic applied behavioral principles. The training was provided using a package entitled “Overcoming Obstacles to Dental Health,” which was described earlier in this report.

Training was conducted at different times for each of the three facilities. Each caregiver training session was conducted by two instructors. A total of four different instructors were used. Instructors were active participants in the development of the training workbook. Additionally, they completed more than 10 hours of preparatory review and practice prior to conducting the caregiver training classes. The same training protocol was used for each of the training classes.

Caregiver training consisted of two, three-hour classes per facility. During the first class, a pre-test was administered; the caregivers viewed a videotape and reviewed six chapters in a workbook. The videotape was developed to directly correlate with the material covered in the workbook.

During the second class, the instructors taught the material contained in the remaining six chapters of the workbook. The caregivers viewed the videotape for a second time and a post-test was administered.

Training classes were held across two consecutive days for one house, in one training day for another house and within one week for the third house. Instructors carefully followed the material contained in the workbook. Review questions were answered and discussed following completion of each chapter. Instructors answered questions posed by the caregivers and used some examples not contained in the training materials. Caregivers completed an evaluation of the training materials and classes at the end of the second class. They received a certificate of completion for their attendance in the classes. Field observations continued after the caregivers received training using the same procedures as during baseline.

**Specific Instruction Phase:** From visual analysis of the data collected from videotapes, as well as from field observer’s comments, it was determined that caregivers were not actively nor consistently supporting clients during toothbrushing sessions. The researchers made a direct statement to the caregivers to work with...
the clients to teach toothbrushing in two homes (City #1 and City #2) following the training phase. In City #3, the training phase included specific instruction for caregivers to work with the clients to teach toothbrushing.

Coaching and Feedback: Field observers provided ongoing verbal feedback and made supportive suggestions to caregivers during this phase. The feedback was directly related to material covered during the caregiver training classes. When the caregiver was present and assisting a client during toothbrushing, the field observer offered verbal directions.

Reliability: Reliability measures for the duration of toothbrushing and caregiver presence scores were obtained by having a second observer review videotaped toothbrushing sessions. The second observer worked independently from the primary observer. Reliability on OHI-S scores was obtained by having a second field observer examine the clients’ teeth after the initial examination was completed. Field observers scored the OHI-S sheets independently. Reliability for all measures was calculated by dividing total agreements by total agreements plus disagreements multiplied by 100.

Results
In the three homes, the total elapsed time of this investigation, from inception of the baseline phase to conclusion of the coaching phase, was 154 days in City #1, 142 days in City #2 and 156 days in City #3.

Dependent Measures
Figure 1 presents graphs of three dependent measures in the three homes. The measures are the duration of brushing, plaque scores and caregiver presence during the oral hygiene sessions. The data for duration of brushing and plaque scores represent a mean value of the data points for all clients in the home on each day that observations were made. The data for caregiver presence represent a mean value for each home for each phase of the study. In order to present all these measures on the same graph, each is plotted as the percent of the maximum score for that measure.

Caregiver Presence
The phase mean for caregiver presence during oral hygiene sessions was 100% for all clients after the coaching phase. This represents an increase for all clients in all homes from baseline. In City #1, there was a caregiver present an average of 63% of the time during baseline. It dropped to 53% after the six-hour training, then rose to 93% after the instruction to use the training and to 100% during coaching.

In City #2, caregivers were initially present an average of 25% of the time in baseline, but they were not present at all after the six-hour training. Their presence rose to 88% of the time after instruction to use the training and then to 100% during coaching.

In City #3, caregivers were present only an average of 11% of the time prior to the six-hour training and instruction to use the training. It rose to 93% after those instructions and to 100% in the coaching phase.

Duration of Brushing
Duration of brushing improved for all clients from baseline to coaching. During baseline, the phase mean on this measure for individual clients ranged from 20.5 to 73.8 seconds. After coaching, it ranged from 57.9 to 215.4 seconds. These represented improvements in the phase mean for individual clients on this measure.

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<td></td>
</tr>
<tr>
<td>Client #2 City #3 4.88</td>
<td>5.25</td>
<td>0.37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client #3 City #3 4.88</td>
<td>5.50</td>
<td>0.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client #4 City #3 4.25</td>
<td>4.50</td>
<td>0.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client #5 City #3 4.88</td>
<td>5.38</td>
<td>0.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client #6 City #3 4.88</td>
<td>5.00</td>
<td>0.12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Daily mean toothbrushing duration, plaque scores and phase mean of caregiver presence for each of three homes.
Timing of Changes in the Dependent Measures

It can be seen in the data presented in Figure 1 that in all the homes, the phase at which there was improvement in the duration of brushing was also the phase in which there was improvement in the plaque scores. The graphs depict the lines for duration of brushing and plaque scores crossing after instruction to use the training in City #2 and City #3, and after the initiation of coaching in City #1.

Social Validation Questionnaire

Pre- and post-study questionnaire results for the three homes are presented in Table 3. The results demonstrate that the caregivers’ perceptions of each participant's competence in oral hygiene changed, although the average scores showed only a slight increase. More specifically, caregivers believed that 8 out of 11 clients improved their oral hygiene abilities following this research investigation.

One month following the completion of field observations, caregivers were contacted by telephone and asked to respond to six questions. The questions served as additional social validation data for the research investigation. Three out of three caregivers contacted answered survey questions. A summary of the responses are presented in Table 4.

from baseline to the coaching phase of 34.0% to 518%. The plot of the daily mean values for this measure is depicted in Figure 1.

In City #1, the length of brushing demonstrated no relative improvement until the coaching phase. In City #2, the improvement in this measure started after instruction to use the training and was sustained during the coaching phase. In City #3, it improved after the six-hour training and instruction to use the training, and then further improved during the coaching phase.

Plaque Control

Since the plaque score is a measure of plaque remaining on the teeth after brushing, it should decrease with improved oral hygiene. In fact, there was a decrease in this measure with all clients from baseline through the coaching phase. The phase mean plaque scores for individual clients during baseline ranged from 2.1 to 1.0. During the coaching phase the range was from 1.6 to 0.3. This represented an improvement from baseline through the coaching phase of from 18.8% to 72.5%.

As the plot of the daily mean values for this measure depicted in Figure 1 shows, in City #1, the plaque score did not improve until the coaching phase. In City #2, the improvement in this measure started after instruction to use the training and began to revert toward the baseline values during the coaching phase. In City #3, it improved after the six-hour training and instruction to use the training, and the improvement was sustained during the coaching phase.

<table>
<thead>
<tr>
<th>Location</th>
<th>Benefits of Study</th>
<th>Problems with Study</th>
<th>Changes Since Study B</th>
</tr>
</thead>
<tbody>
<tr>
<td>City #1</td>
<td>Clients’ oral hygiene improved</td>
<td>At times we forgot about the study (to be prepared for the observations).</td>
<td>More time is spent brushing. Taught clients new (skills).</td>
</tr>
<tr>
<td>City #2</td>
<td>It (caregiver training) helped everything.</td>
<td>Observations were too frequent. One time a week would have been better.</td>
<td>More time spent brushing. Video served as teaching tool for clients as well.</td>
</tr>
<tr>
<td>City #3</td>
<td>Better knowledge of what clients are actually doing. Suggestions for modifications were very helpful.</td>
<td>Amount of time in the study (too much staff time required).</td>
<td>All clients now floss weekly. Have made modifications for some clients.</td>
</tr>
</tbody>
</table>

### TABLE 4

Results of Social Validation Phone Survey: Post-study

<table>
<thead>
<tr>
<th>Location</th>
<th>Benefits of Study</th>
<th>Problems with Study</th>
<th>Changes Since Study B</th>
</tr>
</thead>
<tbody>
<tr>
<td>City #1</td>
<td>Clients’ oral hygiene improved</td>
<td>At times we forgot about the study (to be prepared for the observations).</td>
<td>More time is spent brushing. Taught clients new (skills).</td>
</tr>
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<td>City #3</td>
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<td>All clients now floss weekly. Have made modifications for some clients.</td>
</tr>
</tbody>
</table>

### TABLE 5

Reliability by Location and Dependent Measures

<table>
<thead>
<tr>
<th>Name</th>
<th>Duration</th>
<th>Caregiver Pres.</th>
<th>Plaque Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client #1, City #1</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Client #2, City #1</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Client #3, City #1</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Client #4, City #3</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Client #5, City #3</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Client #6, City #3</td>
<td>Mean &amp; Range</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Reliability measures were obtained for the three dependent variables across all clients and phases of this research investigation. A summary of reliability measures taken is presented in Table 5.

Reliability of the duration measure was obtained for a total of 34.89% of the observations in the study. Reliabilities of the duration measure for all clients ranged from 85% to 100%, with mean reliabilities ranging from 99.7% to 100%. Reliability of the caregiver presence score was obtained for a total of 32.9% of the observations in the study. Reliabilities of the caregiver presence score for all clients ranged from 90% to 100%, with mean reliabilities ranging from 99.7% to 100%. Reliability of the plaque scores was obtained for a total of 30.5% of the observation in the study. Reliability of the plaque scores for all clients ranged from 67% to 100%, with mean reliabilities ranging from 78.57% to 96.33%

Discussion

Study Methodology

The results of this study are important because positive effects were demonstrated on oral hygiene measures using an indirect training methodology. Caregivers were trained, but the ultimate effects were demonstrated in the clients. In addition, these effects were demonstrated in community care settings. This study showed that training and coaching could have beneficial effects on caregiver and client behavior and the client's oral hygiene.

Although it was expected that the most significant changes would be observed following the coaching phase, some improvement was also expected after the training sessions. It was observed that after the training in City #1, caregivers had not begun to actively use the information they had gained. Additionally, the presence of caregivers during oral hygiene sessions following the training decreased. Although there is no empirical evidence, an explanation could be that since the caregivers had completed the training and received continuing education certificates, they believed that their part in the study had been completed. Therefore, the researchers modified the design to include a specific instruction to use information provided during the training.

Dependent Variables

In general, there was an improvement in all of the dependent variables. Caregivers' participation in their client's oral hygiene activities increased as demonstrated by the fact that they were present during 100% of the toothbrushing sessions by the end of the study. The clients brushed longer, and there was a decrease in their plaque scores. Reliability of the observed data was demonstrated on all the dependent measures. Based on social validation measures taken before and after the study, the caregivers perceived that a majority of the clients improved in their oral hygiene abilities.

In baseline, caregiver presence during oral hygiene sessions was sporadic. Caregivers did not perceive their role as active participants in oral hygiene sessions. In fact, their presence decreased after the training sessions, as discussed earlier. It wasn't until the caregivers were given specific instructions to use the information that their presence increased. This implies that training alone was an insufficient catalyst to have the caregivers apply the learned techniques. Their lack of response to the training sessions demonstrated the importance of clear and specific instructions to apply the knowledge that had been gained during the training sessions.

The duration of brushing increased in all clients in all homes. It did not increase in the same phase of the study in all homes, however. In City #1, the increase in duration of brushing did not occur until the coaching phase, while it increased after training and instruction in City #2 and City #3. The caregivers were present during oral hygiene sessions in City #1 after instruction, but were apparently not effective at changing their clients' behavior in that home until they were coached. They were observed on the videotapes as being present during oral hygiene sessions but not actually working with the clients until the coaching phase.

The change in plaque scores followed the same pattern as the duration of brushing in the three homes. In fact, the data indicated that an increase in
toothbrushing duration was related to a decrease in plaque scores. Longer brushing durations were correlated with decreased plaque scores.

There was variability in the data for all the measures. From observations on the videotapes, it appears that much of the variability is due to normal daily variability in performing personal hygiene tasks plus the effects of group home scheduling, caregiver or client illness, mood swings and other competing contingencies. The effect of these factors may have been exacerbated by the lack of a reinforcement plan for the caregivers after the training phase.

**Caregiver Participation**

Although there was general improvement in all the dependent measures in this study, the issue of caregiver participation was problematic for the researchers throughout the project. The caregivers, as discussed earlier, needed clear and precise instructions before they were routinely present during oral hygiene sessions. Even then, those in City #1 needed further precise instructions before they actively worked with the clients. These results point to an imprecise understanding about caregiver motivation and behavior with regard to participation in personal care and disease prevention activities of their clients.

**Directions for Further Research**

In spite of the encouraging results of this investigation, conclusions cannot be drawn about the applications of this training model to settings where improvements in clients’ oral hygiene are not valued by caregivers. Further research should include investigations designed to clarify factors that contribute to caregiver participation in programs of this type. The broader issue is the question of what influences caregivers to use health promotion practices with their clients with disabilities.

The results of this study demonstrate that oral hygiene measures can be improved for clients with mild-to-moderate mental retardation in community care settings. Since improvement followed different interventions in different homes in this study, a precise protocol for this improvement cannot be established. It was demonstrated that the combination of clear instructions and coaching was effective for all participants in this study. Conclusions about the results of this type of program in other settings, such as institutions and private homes, or over extended periods, would require replication in varied settings and the use of longer-term longitudinal studies.

Another area for future research is whether managers of residential care facilities can successfully train and monitor their own staff or employees to understand and use behavioral and preventive dentistry techniques with their clients.

**Summary**

The advantages of this type of training approach are that it is relatively low in cost and relatively easy to implement. The training materials were designed to be used without additional props, materials or preparation by the trainers. This type of training approach was designed to be applied in rural areas and in diverse settings. In addition, the instructional skills on behavior management techniques contained in the training were designed to be applied to caregiver supervision of other areas of personal hygiene or activities of daily living. Finally, this approach can be implemented with local community-based personnel and does not require the involvement of dental or behavioral professionals.

This investigation demonstrated that an indirect training method in suburban and rural residential care settings produced improvements in caregiver and client behavior and the clients’ oral hygiene. Additionally, caregivers stated their general satisfaction with the training program. The shifting responsibility for personal health care of persons with disabilities toward the managers and staff of community-based facilities make it imperative that cost effective, easy-to-use, community-based training and coaching programs be made available for these caregivers. There is much work to be done to clarify the multiplicity of factors that contribute to the application of caregiver knowledge in personal care practices.

**REFERENCES**


Slipping Through the Cracks

DENTAL CARE FOR OLDER PERSONS WITH INTELLECTUAL DISABILITIES


Abstract
An increasing population of men and women with intellectual disabilities and other developmental disabilities is reaching older ages. As our country continues the process of deinstitutionalization, these individuals will require treatment in communities. Dental practitioners increasingly will be involved in the needs of this population, many of whom are members of families being treated in private dental practices. A review of these developments and the particular dental needs of these patients is considered.

“THERE ARE AN estimated 526,000 adults age 60 and older with intellectual disabilities and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy). Their number will double to 1,065,000 when all of the post-World War II ‘baby boom’ generation, born between 1946 and 1964, will be in their sixties.”

People with intellectual disabilities (ID) grow up, grow old and need health care services. “But people with ID (and) their families…report exceptional challenges in staying healthy and getting appropriate health services when they are sick.” As the general population ages, health practitioners increasingly will be called upon to provide care for older individuals with cognitive impairment, including Alzheimer’s disease and other forms of dementia, as well as older persons with intellectual disabilities.

Increasing Life Expectancy
The life expectancy of people with conditions associated with ID has lengthened to a greater extent than one might have considered possible just a few years ago. For example:

- The average age of death for people with intellectual difficulties increased from only 19 years in the 1930s to 59 years in the 1970s and 66 years in the early 1990s.
- Life expectancy for persons with Down syndrome increased from 9 years in the 1920 to 56 years in the early 1990s. The rate of increase during the 1980s and 1990s was eight-times the rate of increase of life expectancy for the general population.
- It is anticipated that the number of adults with developmental disabilities who are 60 and over will increase three-fold over the next 20 years.

Deinstitutionalization
In addition to increases in life expectancy, there has been a dramatic transformation in residency for individuals with intellectual disabilities and developmental disabilities (ID/DD). At one time, there were more than a quarter of million individuals with ID/DD in state institutions and psychiatric facilities. By the end of the last century, the number of institutionalized residents decreased by...
75%, a 91% decrease of residents with ID/DD in psychiatric facilities. Deinstitutionalization has led to the establishment of community-oriented group residences, adult assisted-living facilities and the enhancement of personal family residential settings.

In the past, large state institutions offered a wide range of in-house services provided by the medical and dental staff. Although many institutions were underfunded and understaffed in direct care and professional services, many large state facilities had a dental clinic. In many instances, deinstitutionalization has resulted in a breakdown in the continuity of services. Thus, residency changes have added great numbers of individuals with special health needs to the many individuals with ID/DD who always lived in our communities, and has complicated further the efforts to secure needed health services, including dental care.

As with other populations, health promotion and disease prevention is multi-faceted for individuals with ID. Routine preventive services, from periodic oral prophylaxis and restorations, to cancer screening, immunizations and early intervention of services are critical to prevention of more serious conditions and secondary disabilities. But, as a result of deinstitutionalization, the needs for health services for individuals with ID/DD increasingly have become the responsibility of community practitioners (practitioners, who may be treating other family members of individuals with ID/DD).1,2

**About Intellectual Disabilities**

**Mild ID**

Eighty percent of people with developmental disabilities are mildly retarded. Most practitioners will be called upon to provide services for this population with mild forms of ID/DD. Generally, people with mild intellectual disabilities live with their families or in their own home or apartment. Children attend school. Adults need help with money management, household skills and job coaching for typical job settings. They need minimum structured arrangement.

**Moderate ID**

Eighteen percent of persons with developmental disabilities have moderate ID. Most children live at home; they receive respite and personal help. Adults need help with money handling, shopping, cooking, household skills and public transportation. Adults generally need more structure and more supervision to live in their own homes.

**Severe ID**

Two percent of persons with developmental disabilities have severe ID. Generally they need 24-hour supervision and structure provided by family members or other care providers. They need support and training with basic self-care functions, including eating, dressing, grooming and toileting. Adults need additional help with money handling, shopping, cooking, household skills and public transportation. Employment needs must be very structured.3

**Type of Dentistry Required**

No nationwide studies have been conducted to determine the prevalence of dental diseases among the various populations with disabilities. Numerous local and regional reports, however, provide a general appreciation of the needs. The population with disabilities has significantly higher rates of poor oral hygiene, gingivitis and periodontitis than do members of the general population. There is a wide range of caries rates among people with disabilities, but, overall, their rate is significantly higher than that of the general population. Much of the variation stems from where the people live, that is, institutional settings, community residential facilities or home settings.4,5,6

Various factors related to an individual’s disability, such as articulating the source of oral pain, may make it more difficult to prevent and treat dental disease. The actual treatment also may differ because oral disease often is presented at a later stage and treatment must often be adapted to the individual’s physical and cognitive impairments.7

Some specifics:

- Poor oral hygiene is a common problem. Individuals with an intellectual disability may not understand how to take care of their own oral hygiene, and others with a physical disability may not be able to accomplish it. Personal caregivers often are negligent in providing help with oral hygiene because of lack of education. (An extremely high staff turnover rate is an additional contributing factor.)

- The complicating physical limitations of arthritis are a reality for many of the elderly, including older persons with ID/DD. For example, arthritic constraints may complicate the insertion and/or removal of a partial denture.

- There is a higher incidence of malocclusions resulting from a history of contributing factors, such as craniofacial deformities, abnormal tongue posture, orofacial muscle disturbances, aberrations in growth and development, or difficulties in behavior management that ruled out interception or complete orthodontics.

1. In 1999, the United States Supreme Court issued a decision in the case of Olmstead v. L.C., 119 S. Ct. 2176 [1999]. This case involved a challenge under Title II of the Americans With Disabilities Act (ADA), 42 U.S.C. § 12132. In the decision, the Court held that a state is required under Title II of the ADA to provide community-based treatment for persons with disabilities who live in, are “at risk” of living in, or are eligible for placement in facilities or institutions. Under the decision, persons with disabilities have a right to live in the community if:

- They and their treatment teams agree that they can live successfully in the community;
- They choose to live in the community; and
- There are resources available to help them live in the community.3

2. See previous presentations in The NYSDJ for 1) an extended review of changing residential settings of individuals with ID/DD and impact on community dental practices, and 2) the number of youngsters with disabilities in New York State, many of whom will grow to adulthood and older years.8

3. Where not specified, material on the specifics on dental services was drawn from the extended publication Aging with Intellectual Disabilities, for which one of us (SPP) provided clinical input.9
Among individuals with Down syndrome, there is a high rate of periodontal disease, congenitally missing teeth, anomalies in tooth form, shorter crown/root ratio and early tooth loss.14

A more frequent occurrence of bruxism, along with dyskensia (involuntary movement disorders of the facial and limb muscles) and other movement disorders is seen.15

Xerostomia (dry mouth) is a common oral health problem and may be associated with a wide range of medications for high blood pressure, heart disease, diabetes, allergies and depression. Changes in salivary flow may impair denture retention and increase oral trauma from dentures. Reduced salivary flow is associated with increased burning/ soreness of oral tissues, difficulty in chewing, speaking, swallowing, oral infections and increased decay, all of which can affect adversely food selection and dietary compliance.

Mouth breathing, related to small nasal airways, contributes to fissured tongue and lips.

Mutilated dentitions, particularly of anterior teeth, are often associated with poor ambulatory skills, past history of trauma due to seizure activity or some behavioral tendencies of repetitive bodily movements, and fixation on certain tasks. These tasks may include chewing on hard, non-edible objects that tend to fracture teeth.

The fracture of anterior teeth may be associated with physical abuse. There are increasing reports of physical, sexual abuse, exploitation and neglect of the general elderly population, including the elderly with ID/DD, as mounting numbers of individuals reach advanced years.15-17 (4) Indeed, “millions of elderly live in fear of abuse.”15

Halitosis often is associated with upper respiratory conditions caused by excessive mucous buildup, infections or even poor digestion, but might also result from poor oral hygiene, large cavities or advanced periodontal disease.

Regurgitation (rumination) is a characteristic seen in many individuals with moderate or profound mental disabilities. Swallowing of food, followed by regurgitation, may lead to severe indigestion, malnutrition and erosion of teeth. Excessive drooling of saliva may be associated with regurgitation and pouching (accumulation of food between cheeks/lips and gums) or pocketing.

Treatment plans should be formulated according to standard practices with specific consideration of:

- The patient’s pain or infection.
- The patient’s medical status and medications, including prescribed items, as well as herbs and supplements. A multidiscipline approach to care often may be necessary.

4. “90% of people with developmental disabilities will experience sexual abuse at some time in their lives.”18
The patient’s mental status—level of disability, understanding and communication, psychological and social needs.

- The effects of the current oral condition on the quality of life.
- Physical impairments.
- Patient capacity for care management.
- Financial considerations.

**Barriers Exist**

**Lack of Basic Knowledge**

Repeated studies have shown that dental and dental hygiene school graduates do not gain the necessary expertise to treat elderly patients, including those with ID/DD. For example:

1. A recent study of U.S. dental schools indicated that didactic teaching in geriatric dentistry has increased markedly in the past two decades, but “…clinical experience, both intramurally and extramurally, did not keep pace.” A study of U.S. and Canadian dental hygiene schools concluded that “…current levels of geriatric…education may not meet the increasing demands of this growing population.”

2. Results of a study of U.S. and Canadian dental schools carried out at the end of the 1990s showed actual decreases in the allocation of time for training students in the care of services for individuals with ID/DD over the four years of education. More than half of the schools provided fewer than five hours of didactic training. Almost three-quarters of the schools provided 5% or less of clinic time for care of patients with ID/DD.

3. Results of a regional 2001 study of third- and fourth-year dental students’ attitudes, beliefs and training experience related to individuals with intellectual disabilities mirrored the findings of the previous studies. Almost two-thirds (63%) of students reported they have never treated an individual with intellectual disabilities. Eighty-two percent of students reported fewer than five hours of didactic time devoted to treating these patients with special needs.

4. A national study of dental hygiene programs reported comparable findings.

5. As a result of efforts initiated by Dr. Waldman and Dr. Perlman, under the auspices of Special Olympics, the Commission on Dental Accreditation adopted new standards that became effective this year for all dental and dental hygiene education programs. The standards require that “Graduates must be competent in assessing the treatment needs of patients with special needs.” These individuals include, but are not limited to, people with developmental disabilities, complex medical problems and significant physical limitations.

**Third-Party Payments**

Recent changes in national economics have had a dramatic impact on state finances. Despite increases in the number of individuals adversely affected by the downturn in the economy, state governments have sought to limit increases in taxes while trimming budgets—particularly in areas in which spending is not required by federal and state legislation, e.g., adult Medicaid dentistry. (Note: Medicaid dental care is mandated for eligible children under the Early Periodic Screening, Diagnostic and Treatment Program, but it is an elective service for adults.)

- For example, between 2000 and 2003:
  - The number of states that provided full Medicaid dental services to adults decreased from 14 to 4.
  - In addition to the District of Columbia, the number of states that provided no Medicaid dental services to adults increased from six to seven, with eight more states proposing to eliminate adult services.
  - There was an increase from 13 to 20 states that provided or proposed to provide only emergency adult dentistry.

Note: Except for specific limitations, Medicare does not cover dental services. Thus, the elderly with financial limitations are dependent upon the continuing decreasing availability of adult Medicaid dental coverage for services.

Only the states of New Mexico, New York, North Dakota and Pennsylvania have provided the full range of adult Medicaid dental services since 2000, with no apparent current legislative efforts being made to modify these services. In addition, the full range of dental services has been provided in New Jersey. Efforts had been made in 2003, however, in New Jersey to eliminate all adult services.

**General Population Projections and Dental Practice**

In 2001, 35.3 million residents (12.4%) of the U.S. were 65 years or older; 1.5% were 85 or older. By 2025, almost one-in-five persons in the country (82 million) will reach the “golden-age milestone”; 2.2% (17 million) will be 85 or older. (5)

Note: The reality is that the 65-age mark should not hold as the single standard for many individuals with intellectual disabilities and other developmental disabilities. The years of physiological aging for this population may take their toll at a more rapid rate, with the result that these individuals may be considered in need of care “from a geriatric perspective” at a far earlier age. “Two-thirds of the states define ‘old age’ for (persons with ID/DD) to be 55 years.”

Health providers increasingly will be involved in the needs of this growing population. They include a series of complex physical,

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5. The historic precedent for the adoption of 65 (as the senior citizen milestone age) dates to the time in 1883, when Otto Von Bismarck, chancellor of Prussia, selected it for the establishment of the world’s first national social benefit program — because so few people lived to that age.
psychological and, yes, dental needs. This is an age cohort that consumes lengthening lists of pharmaceuticals, and, in many instances, has intellectual, economic and residential difficulties, as well as a seemingly endless array of other complicating factors. Individuals with intellectual disabilities, who are living to older ages and living in community settings, will be a part of this increasing aging patient population in many dental practices.

Unfortunately, from the perspective of older individuals, including those with ID/DD, all too often,"...a health-care provider attitude (can be) summarized by the remark, 'You're just getting older...what do you expect?'" (sic) How well prepared are you and your staff for these eventualities?

REFERENCES