

President's Committee for People with
Intellectual Disabilities



KEEPING THE CHARGE

Accessibility to Dental Care
for
People with Intellectual Disabilities

2005

DISCLAIMER

This document, *Report to the President: KEEPING THE CHARGE...Accessibility to Dental Care for People with Intellectual Disabilities*, does not necessarily reflect the views of the United States Department of Health and Human Services.

Although some of the information and data contained in this Report were contributed by authorities in the field of disability, public policy, dentistry and related fields, the personal opinions that such contributors may hold or choose to express outside of this Report do not necessarily reflect the views of the President's Committee for People with Intellectual Disabilities or the United States Department of Health and Human Services.

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

As Chair of the President's Committee for People with Intellectual Disabilities (Committee), I am pleased to forward to you a copy of the Committee's annual Report in keeping with your Executive Order 12994, as amended. As requested in the Executive Order, the Report is being delivered to you through the Secretary of Health and Human Services.

The President's Committee for People with Intellectual Disabilities has recently discovered some important findings concerning an overwhelming percentage of American citizens with intellectual disabilities. Most citizens with intellectual disabilities possess varying degrees of poor dental health, which frequently transmit to a detrimental effect on their overall general health.

The cost for a preventive approach to dental health care is relatively low, but the costs for neglecting preventive dental health care measures are enormous to this vulnerable population. The Committee desires to help alleviate the economic impact of this situation on our nation, and at the same time, improve the health status of our American citizens with intellectual disabilities.

As a result of its findings, the Committee is submitting to you this Report citing the deplorable status of dental care of American citizens with intellectual disabilities. The members of the Committee, all appointed by you, are deeply concerned about the issue as described in the Report and have suggested recommendations for your consideration and possible action.

In addition to the requirements described in Executive Order 12994, as amended, the Committee seeks to abide by the purposes and intentions of your *New Freedom Initiative* for people with disabilities as issued by you in February 2001.

I am particularly pleased to serve as Chair of this Committee and support the goals cited in your *New Freedom Initiative* for people with disabilities and all other related activities of your Administration.

Mr. President, thank you for accepting and considering the contents of the enclosed Report. I trust that you will find the Report to be a worthy contribution to your Administration. It focuses on a critical area of concern for our nation which touches most individuals with intellectual disabilities and their families.

Sincerely,

Madeleine Will
Chair
President's Committee for People with Intellectual Disabilities

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Introduction

It is estimated that approximately six million Americans of all ages, or up to three percent of the general population of the United States of America, experience intellectual disabilities (mental retardation). Nearly 30 million families, or one in ten, are directly affected by a person with intellectual disabilities at some point in their lifetime. Intellectual disabilities present a major challenge to the social, educational, health and economic systems within the United States.

The President's Committee for People with Intellectual Disabilities was first established in 1966 by Executive Order to focus on this critical subject of national concern. Since 1966, the Committee has fostered State planning, stimulated development of strategies, policies and programs and advanced the concept of community participation in the field of intellectual disabilities. The Committee's primary function is to provide advice and assistance to the President of the United States and the Secretary of Health and Human Services on a broad range of matters relating to programs, services, supports and policies that impact the lives of people with intellectual disabilities and their families.

In February 2001, President George W. Bush expressed his commitment to tearing down the barriers to equality that challenge millions of Americans with disabilities. The President announced his *New Freedom Initiative*, established to help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of people with disabilities to integrate into the workforce and promoting increased access into daily community life. At its first meeting, the President's Committee determined that it would organize its advice to the greatest extent possible within the conceptual framework of the challenges and goals outlined in the President's *New Freedom Initiative* for people with disabilities.

Providing core ideas to change the reality that millions of people with intellectual disabilities remain outside of the mainstream of American life motivated the Committee to examine the current state of dental care for persons with intellectual disabilities.

Accessibility to Dental Care for People with Intellectual Disabilities

The Issue of Dental Care for People with Intellectual Disabilities

The President's Committee for People with Intellectual Disabilities has recently investigated the current state of dental care for the full range of American citizens with intellectual disabilities. The Committee has discovered a number of important facts and findings through its investigation of the status of dental healthcare for people with intellectual disabilities. Broadly, it has found that the status of dental healthcare is appalling for these citizens of our nation. Consequently, the President's Committee is calling upon the Administration to carefully consider the recommendations incorporated in this Report to remedy a very grave challenge for our country.

The President's Committee for People with Intellectual Disabilities believes that by considering the recommendations in this Report to the President, the Administration would be able to address the underlying issues associated with poor dental healthcare for these Americans. The Report addresses issues relating to proper recognition and designation of this population as an underserved population in dental healthcare; acknowledges and encourages action for improved professional education and training in dental healthcare for this population; presents data supporting the need for increasing and correcting the level of public awareness for this population; and highlights several other related areas. The recommendations in this Report are carefully aimed at remedying and improving the overall quality of dental healthcare for American citizens with intellectual disabilities in the most effective and efficient manner.

Among advocates, self-advocates and healthcare experts, it is agreed that the lack of adequate dental care for people with intellectual disabilities is an epidemic that detracts from the quality of life of these individuals and places them at increased risk for associated medical problems that frequently result in higher costly visits to the emergency room with additional treatments.

In a recent survey screening of Special Olympics athletes whose average age was 24, it was found that nearly one in eight people with intellectual disabilities had a pain-causing lesion in their mouth, one in six had untreated decay and one in four were already missing teeth.¹ While it is estimated that over half of people with intellectual disabilities have periodontal disease, some sub-populations with specific neurodevelopmental diagnoses, such as Down Syndrome, have periodontal disease rates as high as 96percent.² Periodontal disease, a chronic infection caused by oral bacteria, has been linked with an increased risk of stroke, myocardial infarction and the likelihood of having a premature, low birth-weight infant.³

There have been numerous Reports detailing the significant healthcare disparities experienced by people with intellectual disabilities, both in terms of healthcare access and healthcare quality. Perhaps the most significant study was published in the Surgeon General's Report of 2000.⁴ This Report stated that lack of provider education and poor

provider reimbursement were two important factors contributing to the general lack of access to quality healthcare for people with intellectual disabilities.

The findings of the Committee's investigation on dental healthcare and the resulting recommendations are reported below. It should be noted and made clear that the statements in the findings of the President's Committee may address a broader area of concern than the recommendations. However, since some of these findings address matters pertaining to legislation, the legislative aspects are not included within the recommendations.

The Committee's recommendations are designed for the special attention and consideration of the President and the Secretary of Health and Human Services (HHS) so that they may be implemented without the need for any major legislative change or approval. At this time, the President's Committee believes that some of the most important actions pertaining to the dental healthcare status of American citizens with intellectual disabilities may be addressed directly by the Administration.

The Committee is well aware of the many conversations and deliberations taking place at the Federal and State levels of government to make improvements to the Medicaid program. This program is among the most important in all of government to persons with intellectual disabilities because of its far reaching impacts on health care, housing, employment and other services and support areas. The Committee would like to respectfully offer a strong caution that policymakers involved in developing Medicaid not build their reforms on short-term actions that undermine the long-term interests of this underserved and vulnerable population and the overriding importance of providing preventive care and supports.

Findings of the Committee - Professional Education and Training

The American Academy of Developmental Medicine and Dentistry (AADMD), through a grant from Special Olympics and the Center for Disease Control and Prevention (CDC), recently performed a comprehensive national survey of medical and dental education in the United States regarding people with intellectual disabilities. In this study, it was found that the majority of dental schools did not consider intellectual disabilities to be a priority subject, despite the fact that up to six million people in the nation may have intellectual disabilities. It was also found that the majority of dental students will graduate from dental school having never observed or treated a patient with intellectual disabilities.⁵ Furthermore, it was found that the majority of dental residency programs also do not address intellectual disabilities. Finally, the availability of continuing education focused on intellectual disabilities for practicing dentists is very limited.⁶

The effect of a lack of provider education has significant consequences for persons with intellectual disabilities. In one study that involved persons with intellectual disabilities who had access to dental care, findings revealed that over 80 percent of the dentists were not performing baseline radiographs, nearly 75 percent were not performing periodontal charting and the majority of people with intellectual disabilities were not receiving two-thirds of the

standard of dental healthcare.⁷ In other studies of persons with intellectual disabilities in settings where the cost of care and inadequate access to care were prevalent factors, the data showed the following: Roughly 25 percent of people with intellectual disabilities had been referred to the operating room to receive their dental care under general anesthesia and 55 percent had been referred for intravenous sedation.⁸

This data should be compared to anecdotal results from highly experienced developmental dentists who Report having referral rates to the operating room of approximately 3 percent and about 5percent referral for intravenous sedation. It should be noted that the use of general anesthesia and intravenous sedation significantly increases the cost of care and also increases the medical risks associated with treatment. In an unpublished study, it has been estimated that providing the proper standard of dental healthcare to people with intellectual disabilities could save over \$1,300 per person per year in avoided medical, dental and sedation costs.³

Findings of the Committee - Public Awareness

Public awareness of the poor dental health status of people with intellectual disabilities is very limited. Studies published by the Special Olympics show that the majority of people believe that individuals with intellectual disabilities receive the same or better dental healthcare as other people living in the United States. However, this is far from the truth. Another common misconception among members of the general public, dental healthcare professionals and government agencies is that dental care is a separate concern from medical care. Yet, periodontal disease, which is rampant in the intellectual disabilities population, is associated with significant increases in many associated medical conditions, since it is known that the mouth reflects the health of the rest of the body. The mouth reflects the general health and well-being of individuals and without good oral health, people cannot be truly healthy.

For individuals, this means that good overall health cannot be achieved without good oral health. There is evidence that chronic oral infections such as periodontal diseases, which are extremely common among people with intellectual disabilities, are associated with systemic diseases such as diabetes, heart disease and stroke. For dental healthcare professionals, this means that physicians should also be concerned about the state of oral health of an individual. For government entities, this means that the failure to cover dental healthcare services for the intellectual disabilities population may require more money to be spent on associated medical conditions that have arisen from chronic oral neglect.

Findings of the Committee - The Economics of Dental Healthcare

Approximately 70 percent of people with intellectual disabilities participate in the Medicaid service system. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) service of Medicaid, which requires dental services for eligible children, is essential for the continuity of dental care provided to the majority of children with intellectual disabilities. Unfortunately, the Committee found that dental healthcare is an optional program for adults over age 21. As a result, a large majority of State Medicaid programs do not cover the full

range of dental services for adults with intellectual disabilities and some have no dental coverage for adults at all.

In essence, this means that the years of investment in the dental health of children and adolescents with intellectual disabilities, who were covered by Medicaid, are lost once they reach adulthood. Furthermore, this means that adults with intellectual disabilities are subject to the medical ramifications of advanced dental neglect that frequently lead to expensive, avoidable and sometimes inappropriate medical interventions such as emergency room visits, psychiatric referrals, neurological referrals and numerous and various drug prescriptions.

Even in the States that do elect to cover adult dental healthcare under Medicaid, many dentists decide not to accept Medicaid patients because Medicaid reimbursements are, in fact, so low that in most cases they do not even cover the cost of providing treatment. A study conducted by the Government Accounting Office indicated that Medicaid dental reimbursement rates in most States are equal to or less than the dental fees normally charged by only 10 percent of dentists (the 10th percentile of respective fees).⁹ These rates are not high enough to cover the business overhead expenses of most private practice dentists (equipment, staff salaries and supplies) which, on average, account for 60 percent of their gross revenue.¹⁰

There are many reasons why dentists are reluctant to treat people with intellectual disabilities. Of the dentists who do participate in Medicaid, many avoid treating patients with intellectual disabilities because these patients may take up to twice as long to treat, due to factors such as behavior control or chronic oral neglect. From a private practice perspective, the extra time involved in treating patients with intellectual disabilities, combined with the low rate of Medicaid reimbursement, means that the revenue generated per hour is prohibitive to potentially willing dentists caring for people with intellectual disabilities.

Regardless of this situation, there are dedicated dental professionals willing to care for people with intellectual disabilities and willing to participate in the Medicaid program. In order to ensure access to these providers, Medicaid dental coverage for people with intellectual disabilities should not only be maintained, it should be expanded to cover dental care of individuals across the life span.

Recommendations of the Committee

The recommendations of the Committee cited below are intended to be supportive of the *New Freedom Initiative* for people with disabilities as issued on February 1, 2001, by President George W. Bush. This includes a commitment by the Committee to support the President's belief "that community-based care is critically important to promoting maximum independence and to integrating individuals with disabilities into community life."

Among all recommendations presented below, the Committee considers the first recommendation to be paramount.

1. Encourage HHS to officially designate people with intellectual disabilities as a "Medically Underserved Population."

Ramifications: The "Medically Underserved Population" (MUP) designation will allow HHS and other grant administering agencies to consider the full range of persons with intellectual disabilities as an eligible category for programs such as health disparities research, medical and dental loan repayment programs and J-1 visa, foreign graduate programs. Such programs, when established in the community, will promote professional, university and research interest in this population as well as increase the number of providers, thus improving access to community-based care in keeping with the *Olmstead Decision* and the *New Freedom Initiative*.

2. Encourage HHS training vehicles to support better training of dental healthcare professionals in the community regarding intellectual disabilities.

Ramifications: Funding for fellowship training programs in developmental dentistry could be made available to encourage their growth and development. Additionally, primary care residency programs such as Internal Medicine, Family Medicine, General Practice Dentistry (GPR), Pediatric Dentistry or Advanced Education General Dentistry (AEGD) should have additional funding made available if they are able to show significant didactic and clinical training activity regarding intellectual disabilities. If additional funding cannot be made available, current funding for these programs should be attached to a requirement that these programs adequately train professionals regarding the care of the full range of people with intellectual disabilities.

3. Encourage continuing education of dental professionals in the community regarding the treatment of people with intellectual disabilities.

Ramifications: There is the need to stimulate the development of expertise among providers to offer community-based quality continuing education to physicians and dentists regarding dental and oral healthcare for the full range of people with intellectual disabilities. Funding for continuing education programs in developmental dentistry should be made available to encourage their growth and development. Additionally, continuing education programs in other areas such as GPR, Pediatric Dentistry or AEGD should have additional funding made available to stimulate increased community-based services for people with intellectual disabilities.

- 4. Encourage model demonstration projects designed to provide high- quality community-based dental care for people with intellectual disabilities; and support the use of technology in the form of Permanente Dental Associates (PDA) based prompting systems for people with intellectual disabilities to “coach” them on personal dental hygiene principles and techniques.***

Ramifications: Community-based programs should be developed that combine services, training and research models focused on the full range of people with intellectual disabilities. When successful, these model programs could be expanded or replicated in a larger scale, community-based, demonstration project. Larger demonstration projects would provide greater opportunity for access to community dental health services, as well as promote better professional training and research. This should include the enlistment of direct care personnel in dental hygiene support. The development of criteria for high quality and community-based dental healthcare services should be included with recognition of the *Olmstead Decision* and the *New Freedom Initiative*.

- 5. Encourage a public awareness campaign regarding better oral health for people with intellectual disabilities.***

Ramifications: There are a number of potential target markets for public awareness campaigns emphasizing better dental health and better overall health for the full range of citizens with intellectual disabilities. Different campaigns may be directed at accrediting agencies for providers of community-based dental healthcare, physicians and dentists, nurses and hygienists, educators, direct care support staff, family members and people with intellectual disabilities themselves. Special attention may be needed for difficult to reach rural communities vs. urban communities. Dissemination of this kind of information should be a priority of all agencies that are authorized to provide services and supports to people with intellectual disabilities.

The Office of the Surgeon General, the CDC and possibly the Centers for Medicare and Medicaid Services (CMS) may partner with private organizations to launch various public awareness campaigns. Additionally, it would be worthwhile to promote the preventive concept among caregivers that dental hygiene recommendations provided by dentists are just as significant as medication recommendations provided by physicians in terms of maintaining the overall health of the individual. Building on this preventive concept will be essential to public and private organizations whose mission is to guarantee adequate community-based dental healthcare for citizens with intellectual disabilities.

- 6. Encourage HHS research vehicles to conduct an epidemiological study on dental and oral diseases among Americans with intellectual disabilities, providing incidence and prevalence data on this vulnerable population.***

Ramifications: There are a variety of sources for data on diseases among the full range of people with disabilities. However, scientifically-based epidemiological

data on dental and oral diseases among people with intellectual disabilities are believed to be either non-existing or rare in number and scope. CDC possesses recognized capability to conduct a scientifically sound epidemiological study on the subject.

Perhaps the National Center for Birth Defects and Developmental Disabilities of CDC, in collaboration with selected Institutes within the National Institutes of Health (NIH), such as National Institute of Child Health and Human Development (NICHD) and/or National Institute of Dental and Craniofacial Research (NIDCR), may be able to forge a partnership to develop a framework for obtaining valid and reliable data on incidence and prevalence of dental and oral diseases occurring in people with intellectual disabilities. The epidemiological study on dental and oral diseases in people with intellectual disabilities must include rural as well as urban areas, and all age groups and consider all racial and ethnic categories.

7. Encourage HHS research vehicles to conduct sample survey studies on the availability and gaps in dental and oral healthcare services for citizens with intellectual disabilities.

Ramifications: In determining the level of availability and/or the extent of gaps in the delivery of professional dental and oral healthcare services to the full range of people with intellectual disabilities, surveys of both urban and rural areas involving subjects from all age groups (young children, older children, young adults and older adults) should be considered to obtain a statistical representative population of persons with intellectual disabilities. Further, studies need to assess the availability or gaps in both preventive and treatment approaches in the delivery of dental and oral healthcare services to this population. It is suspected that vast gaps exist in the provision of dental and oral health services to citizens with intellectual disabilities. Perhaps Health Resources and Services Administration (HRSA), NIH (NICHD and/or NIDCR) and other HHS entities may collaborate to pursue studies on understanding the needs of the population and the levels of responsiveness by the professional dental community to this population.

8. Encourage HHS research vehicles to conduct studies to explore, develop and test new and alternative approaches for increasing and improving the effectiveness and efficiency in quality and quantity of dental and oral preventive and treatment services for persons with intellectual disabilities in our communities.

Ramifications: There is a need for HRSA and NIH (NICHD and/or NIDCR) to consider the exploration, development and testing of new and alternative approaches to the delivery of dental and oral healthcare to the full range of Americans with intellectual disabilities residing in the community. Studies would investigate a variety of innovative models that may improve and supplement existing traditional

approaches to the delivery of dental and oral healthcare services. There should be an examination of the full range of the population, from infancy through old age.

The proposed models need to give special consideration to adults and older adults who may no longer receive Medicaid support, *pro bono* or other sources of services. We need to be cognizant of the fact that many families with children with intellectual disabilities, including adults and the elderly with intellectual disabilities, may have limited resources to access dental and oral healthcare services in the community. Also, the proposed models should consider other portions of the population who may be identified as especially vulnerable and underserved, e.g., individuals with certain clinical syndromes who may pose special challenges to professionals and individuals receiving medications for epilepsy or other conditions or variant behaviors who may be at high risk.

9. Encourage HHS to explore and develop increased access to early screening and prevention services for dental and oral disorders in children with intellectual disabilities through local health departments and maternal and child health programs; and to provide Medical Home of Your Own Plans that support full access to dental and oral healthcare services.

Ramifications: Local Health Departments, through their Maternal and Child Health Programs, have supported services and supports aimed at special populations with disabilities, including the full range of children with intellectual disabilities. These programs provide an excellent opportunity to extend their capabilities to include preventive dental and oral healthcare services to serve these children at early ages in a community setting. Early preventive and screening measures are usually less costly than treatment at later ages.

Concomitantly, local health departments and maternal and child health programs should consider the development of possible dental referral resources in the community for early follow-up care and treatment of children with intellectual disabilities. Any gaps in community follow-up resources should be identified and documented for further consideration and action by community health planners. *Medical Home of Your Own Plans* are to include provisions for full access to dental and oral healthcare for children with intellectual disabilities. Also, assurance should be provided in local health plans for adequate staffing to extend coverage to rural areas in the area of dental and oral healthcare for families with children with intellectual disabilities. Such efforts are clearly in keeping with the *Olmstead Decision* and the President's *New Freedom Initiative* for community integration of people with disabilities.

10. Encourage the U.S. Department of Education to explore and develop increased access to early screening and prevention services on dental and oral disorders in students with intellectual disabilities through its school health and school nursing programs.

Ramifications: Local school systems have often supported school health and nursing services for their pupils. Community-based school programs provide excellent opportunities to expand services and supports for early screening, prevention and treatment in the area of dental and oral healthcare services for children with intellectual disabilities. School health personnel should play a key role in incorporating early screening and prevention processes for promoting dental and oral health among their students. Following screening, school health personnel would relate their impressions to the family for possible follow-up referral by them for professional examinations and treatment.

Teachers are in a unique position to readily observe their pupils in the classroom on a daily basis. It is known that dental and oral health may affect a student's performance and behavior in the classroom, and teachers may observe possible dental or oral health problems. School health personnel should follow-up on any dental or oral health concerns expressed by teachers, just as they would in cases involving accidents, injuries, extreme behaviors, or other health related conditions or emergencies. School health personnel would assume responsibility for any screening, prevention and possible referral to dental or oral healthcare professionals in the community as they may deem necessary.

In association with this, school administrators and/or school health professionals should develop and update on a regular basis community-based referral resources for dental and oral healthcare as they would in cases of any acute or chronic health problem or emergencies that may be observed within the school. Further, community-based health referral resources would serve as a possible advisory resource on dental and oral health for parents and family members should they request such assistance. Such efforts by the school system on dental and oral health are clearly responsive to the *Olmstead Decision* and the President's *New Freedom Initiative* for community integration of people with disabilities.

Conclusion

In order to improve the quality of dental services available for the full range of people with intellectual disabilities living in the United States, the President's Committee for People with Intellectual Disabilities has identified a number of initiatives to be undertaken. It is important to note that the problems leading to the general lack of access to quality dental services for people with intellectual disabilities involve many factors. Any one action taken on its own would not likely produce the desired results. The above recommendations of the Committee are meant to work in concert with each other.

It is important to note that the Committee believes that many of the recommendations affecting dental care are designed to improve the general health status of the full range of people with intellectual disabilities. A more comprehensive and systemic approach to improving the overall health of people with intellectual disabilities would also include greater access to physical and mental health practitioners, services and supports. To address these additional concerns, the President's Committee expects to provide separate recommendations.

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Adult Dental Medicaid Coverage – A State-by-State Overview

ADULT DENTAL BENEFITS IN MEDICAID: FY 2000, 2002, 2003, 2004 & 2005											
	00	02	03	04	05		00	02	03	04	05
Alabama	None					Nebraska	Limited				
Alaska	Emergency					Nevada	Emergency				
Arizona	Limited	Emergency				New Hamp	Emergency				
Arkansas	None					New Jersey	Full				
California	Full					New Mexico	Full			Limited	
Colorado	None					New York	Full				
Connecticut	Full					N Carolina	Limited				
Delaware	None					N Dakota	Full				
Florida	Limited	Emergency				Ohio	Limited				
Georgia	Emergency					Oklahoma	Emergency	None	Emergency		
Hawaii	Emergency					Oregon	Limited				
Idaho	Limited	Emergency				Pennsylvania	Full				
Illinois	Limited					Rhode Island	Limited				
Indiana	Full		Limited			S Carolina	Emergency				
Iowa	Full	Limited				S Dakota	Limited				
Kansas	Limited					Tennessee	Emergency				
Kentucky	Limited					Texas	None				
Louisiana	Limited					Utah	Limited	Emergency			Limited
Maine*	Emergency					Vermont	Limited				
Maryland	Emergency					Virginia**	None				
Mass	Full	Limited	Emergency			Washington	Full		Limited		
Michigan	Full		Emergency			W Virginia	Emergency				
Minnesota	Full		Limited			Wisconsin	Full				
Mississippi	Emergency					Wyoming	Emergency				
Missouri	Limited			none		Dist of Col	None				
Montana	Limited										
As of May 2005											
Key:	Full	Limited	Emergency		None						

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**ADULT DENTAL BENEFITS IN MEDICAID:
50 STATES & District of Columbia
FY2000 - CY2005
As of May 2005**

BENEFIT STATUS	2000	2002	2003	2004	2005
Full	14	12	8	7	7
Limited	17	14	16	18	18
Emergency	13	17	18	19	18
None	7	8	9	7	8

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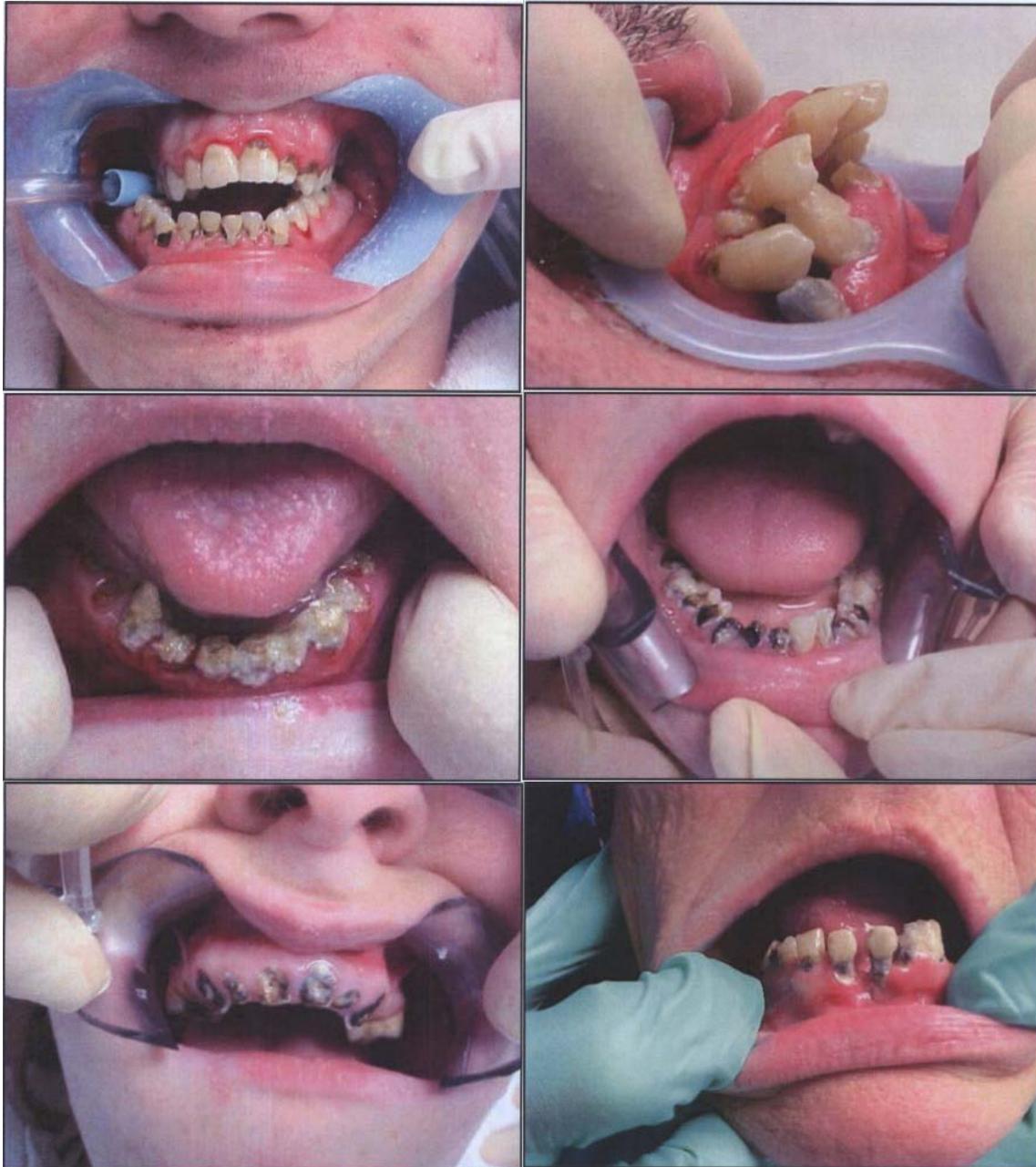


Illustration of conditions commonly experienced by people with intellectual disabilities who have medically and orally complex conditions and who do not receive dental and oral care.

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