Dental Public Health Activities & Practices

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SECTION I: PRACTICE OVERVIEW

Name of the Dental Public Health Activity:
A White Paper on Access to Oral Health Care for Florida's Citizens with Developmental Disabilities

Public Health Functions:
Assessment – Acquiring Data
Policy Development – Collaboration and Partnership for Planning and Integration
Assurance – Building State and Community Capacity for Interventions
Assurance – Access to Care and Health System Interventions

Healthy People 2010 Objectives:
21-2 Reduce untreated dental decay in children and adults
21-4 Reduce adults who have lost all their teeth
21-5a Reduce gingivitis among adults
21-5b Reduce periodontal disease among adults
21-10 Increase utilization of oral health system
6-10 Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

State:	Federal Region:	Key Words for Searches:
Florida	Region IV South Atlantic	oral health care, developmental disabilities, mental retardation, access to care, special health care needs, special needs

Abstract:
For many years the Florida Developmental Disabilities (DD) Council had been made aware of the lack of access to comprehensive oral health care for people with developmental disabilities; however, the information they received was anecdotal. Before the DD Council could approach the state legislature with a budget request aimed at improving access to care, they needed data to support their request. To obtain the necessary data, the DD Council contracted with the Nova Southeastern University College of Dental Medicine and the University of Florida College of Dentistry to manage an information-gathering project that would result in a comprehensive white paper describing access issues and the detrimental consequences of poor oral health experienced by individuals with developmental disabilities. In addition, the white paper was to present realistic recommendations for establishing a statewide oral health care delivery system designed to ensure that comprehensive oral health care would be available to all of Florida's citizens with developmental disabilities. The total budget for the project was $30,000 for costs related to data collection, telephone conferences, travel, and meeting facilities. The white paper provided the DD Council, other state agencies, state universities, state legislators, and the Governor with (1) verifiable data regarding the dental needs of Florida's citizens with developmental disabilities and the lack of access to comprehensive dental care they experience, (2) the causes of the access problem, (3) the detrimental health and behavioral consequences due to a lack of dental care experienced by people with developmental disabilities, and (4) feasible recommendations for establishing an oral health care delivery system that would ensure access to comprehensive care for all of Florida's citizens with developmental disabilities.

Contact Persons for Inquiries:

Paul Burtner, D.M.D., Associate Professor, PO Box 100426, University of Florida, Gainesville, FL 32610-0426, Phone: 352-955-5616, Fax: 352-955-6101, Email: burtner@ufl.edu

SECTION II: PRACTICE DESCRIPTION

History of the Practice:

For many years, both persons within the disability community and the dental profession recognized that access to dental care for person with disabilities was a major problem in Florida. A 1990 study by Burtner and others, **A Survey of the Availability of Dental Services to Developmentally Disabled Persons Residing in the Community** (http://plaza.ufl.edu/burtner/access.pdf), indicated that access to dental care was a concern. However, much of the evidence indicating that access to care was a serious problem in the state was anecdotal, reported by individuals with DD, their parents and siblings, group home operators, social workers/support coordinators, and other interested parties. This scarcity of hard data prevented the Florida Developmental Disabilities Council (DD Council) and other advocates from approaching the state legislature with budget requests aimed at providing needed dental care.

In 2001, the DD Council commissioned the two dental schools in the state, the University of Florida College of Dentistry and Nova Southeastern University College of Dental Medicine to prepare a white paper. In the *Forward* to the White Paper, the Chairman of the DD Council summarizes the problem facing families of persons needing, but unable to obtain, dental care and explains why a white paper was needed to document the problem and provide recommendations for improvement.

The Florida Developmental Disabilities Council deserves much credit for understanding the importance of good oral health for persons with developmental disabilities, and taking the leadership to address the issue. The Council was founded in 1971, to encourage and advocate opportunities for persons with developmental disabilities and their families to enhance their quality of life within their communities. More information about the DD Council and its programs can be obtained from their website at http://www.fddc.org/HOME/index.asp.

Justification of the Practice:

The American Heritage® Dictionary of the English Language, Fourth Edition defines a "white paper" as a government report or an authoritative report on a major issue. The issuance of white papers is a common practice in industry, science, and healthcare (including dentistry). White papers provide an authoritative perspective on important topics as opposed to personal opinion. In the healthcare arena, they are often the product of a team of experts and provide broad policy recommendations to ameliorate recognized problems. A white paper typically argues a specific position or solution to a problem. Although white papers take their roots in governmental policy, they have become a common tool used to introduce technology innovations and products. White papers are powerful marketing tools used to help key decision-makers and influencers justify implementing solutions.

The DD Council anticipated the following advantages in commissioning a white paper as a strategy to improve access to care:

- Although the white paper does not create change itself, it represents a "tool for change" that others can use to advocate for change.
- It demonstrates that the problem has been studied in a systematic, reasoned way by recognized experts in the field as well as individuals who possess intimate knowledge about the subject matter.
- It offers recommendations that represent a consensus among major stakeholders, reducing the possibility of disagreement about strategies for addressing the problem.
- It is a cost-effective approach, as it provides low cost "leverage" for gaining a legislative appropriation that could provide large-scale funding to address the problem.
- It provides a focal point for action, similar to what the Surgeon General reports do at the federal level.
- It provides a cost effective method for disseminating specific information to legislators or grant foundations.

Inputs, Activities, Outputs and Outcomes of the Practice:

Purpose of the White Paper

The DD Council and other interested parties needed evidence to support their budget requests and proposed dental programs when they approached the Legislature. The white paper gathered information and separated fact from supposition. It was seen as the first step in the quest to ensure oral health access for individuals with developmental disabilities. It provided information on the barriers to access, identified the oral health consequences resulting from a lack of comprehensive dental care, and made recommendations for the future. The white paper looked at multiple issues from reimbursement for services (Dental Insurance Plans, Medicaid, Home and Community-based Medicaid Waiver Program, Children's Medical Services, and philanthropic foundations), behavior management, consent issues, dental office equipment needs, dental specialty referral resources, to lack of training and experience and, in some cases, an apparent lack of compassion.

The objectives of the white paper are:

1. To investigate the perceived lack of access to dental services and its consequences for Florida's citizens with developmental disabilities,
2. To identify the causes of this problem,
3. To present potential solutions to the problem of lack of access, such as identifying potential providers, evaluating the merits of strategies implemented by agencies in other states or countries, projecting probable outcomes of a variety of potential solutions, and
4. To make specific recommendations to the Council.

Inputs

The initial input to start the project was a $30,000 grant made to the two dental schools in 2000 to develop the white paper. A Working Group was convened, composed of representatives of the two universities responsible for completing the study. The primary authors of the report were:

- Paul Burtner, D.M.D., Project Director, Associate Professor, Department of Pediatric Dentistry, University of Florida College of Dentistry
- Frank Courts, D.D.S., Ph.D., Principal Investigator, Associate Professor and Chair, Department of Pediatric Dentistry, University of Florida College of Dentistry
- John D. Tabak, D.D.S., M. S., Associate Professor and Chair, Department of Community Dentistry, Nova Southeastern University College of Dental Medicine
- Robert A. Uchin, D.D.S., Dean, Nova Southeastern University College of Dental Medicine

Activities

Following the establishment of the working group, the first activity was an initial planning meeting in February 2000 to clarify project goals, assign responsibilities, establish timelines, discuss budget issues, designate a project director, and begin the process of identifying appropriate members of the "Advisory Committee" charged with oversight of the activities of the faculty from the two universities.

Next, an initial literature review was conducted to ascertain the scope, extent and consequences of the perceived lack of access to comprehensive oral health care in populations with developmental disabilities. At a later date the working group conducted a second literature review to determine what strategies had been implemented in the US and other countries to improve access to care for this special population. This information was important to help develop recommendations.

The working group then contacted community leaders in an effort to identify individuals for membership on the Advisory Committee. The Advisory Committee was composed of parents, oral health professionals representing the Florida Dental Association and Florida Dental Hygiene Association, other health care providers with expertise in providing dental care to this special population, and representatives of governmental and private agencies which provide assistance to people with developmental disabilities. Advisory Members of the Joint Committee represented:

- Individuals with developmental disabilities
- Gulf Coast Autism Association, Inc.
- Florida Dental Association
- Florida Dental Hygiene Association
- Florida's Voice on Mental Retardation
- Medicaid Program Development, Florida Agency for Health Care Administration

- Children's Services Board of Broward County
- Health Care & Prevention, Florida Developmental Disabilities Council
- Florida Hospital Association.
- Department of Pediatric Dentistry, University of Florida College of Dentistry
- Department of Community Dentistry, Nova Southeastern University College of Dental Medicine.

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

The Joint-Committee then discussed and evaluated a variety of access strategies to determine which would be appropriate for implementation in Florida. Based on the findings of the literature review, much deliberation and discussion, and the many years of professional and personal experience acquired by the Joint-Committee members, the Joint-Committee developed recommendations designed to establish an effective care delivery system which, if fully implemented, should ensure access to oral health care for all of Florida's citizens with developmental disabilities.

The preliminary drafts of the white paper were prepared and discussed by the various constituencies at several stages of development. The Chairperson of Florida Developmental Disabilities Council wrote a forward for the white paper. The DD Council designed the cover and the white paper was printed in January 2002.

The DD Council then distributed copies of the final white paper to each legislator in the state, the Governor, the Florida Dental Association, leaders of Florida's two dental schools, stakeholders and other interested parties. Soon after distribution, a presentation was made to the Florida Dental Association's Council on Dental Health.

Outputs

The 2-year process produced the white paper titled **Access to Oral Health Care for Florida's Citizens with Developmental Disabilities** (http://www.fddc.org/LINKS/pdf/AOHCfull.pdf or www.dental.ufl.edu/faculty/pburtner/scdlinks/AOHCfull2.pdf) which was released in 2002.

The white paper consisted of four key sections:

1. *Florida's Citizens with Developmental Disabilities and Oral Health Care*
   The section presents demographic data about people who have developmental disabilities and explores relevant issues that impact their lives on a daily basis. It also explores their success at obtaining needed dental care and the consequences of a lack of oral health care. Demographic data regarding Florida's dentists is presented as well.

2. *What are the Barriers to Access*
   Many factors contribute to the lack of access to comprehensive oral health care for Florida's citizens with developmental disabilities. This section explores and discusses many of the pertinent issues underlying access barriers.

3. *Potential Solutions*
   Lack of access to comprehensive oral health care for this special population is a global concern. This section explores the many attempts to correct this long-standing problem.

4. *Recommendations*
   Based on input from a variety of knowledgeable individuals, a review of the published literature, and the personal experiences of consumers, parents, siblings, and care givers, this section provides recommendations to the Florida Developmental Disabilities Council, which, if fully implemented, would ensure that dental care would be available to people

with developmental disabilities throughout Florida. The recommendations include the following:

- Establish a community-based primary oral health care program where care is provided by private dentists.
- Establish 5 regional education and service centers designed to train and support private community-based dentists and provide treatment to people with disabilities.
- Establish two Centers of Excellence, one at each dental school, to provide treatment for complex cases, train dental students, and conduct continuing dental education.
- Provide adequate reimbursement to dentists, especially for difficult cases.
- Provide an incentive for hospital and other health care professionals to participate in treatment programs.
- For the 2 Centers of Excellence and the 5 regional centers to succeed, there is the need for an experienced full time dentist and at least 2 dental assistants; plus an executive level position and a board of directors.

Outcomes

The outcomes of the white paper included the following:

1. The white paper led to the DD Council funding educational seminars designed to inform dentists throughout the state about the need for comprehensive care for Florida's citizens with developmental disabilities and to provide clinical information about providing comprehensive dental care to individuals with disabilities. These DD Council-sponsored seminars were conducted over a 12-month period and provided continuing education credits.

2. The white paper provided law-makers, agency heads, educators and related organizations with data concerning the number of citizens residing in Florida who have developmental disabilities and their experiences at attempting to obtain comprehensive oral health care from private dental practitioners. The white paper also described the negative behavioral and health consequences resulting from a lack of dental care for this special population. While the DD Council did take action based on the white paper, it is not known if other individuals and agencies took, or are taking, any positive actions as a result of the white paper.

3. When the Robert Wood Johnson Foundation released their Request for Proposals for the **State Action for Oral Health Access** grants in April 2002, Florida had much of the information it needed to begin drafting a proposal related to improving access to oral health care for people with developmental disabilities. Many of the Joint-Committee members became knowledgeable stakeholders when the Governor of Florida assembled the team to apply for the grant.

4. The white paper can serve as a benchmark or template for addressing access to oral health care for people with disabilities residing in other states. For example, after reading the white paper, a team from Drexel University requested assistance in formulating recommendations for the Pennsylvania DD Council. Recommendations from the Florida White Paper formed the core considerations at their DD Council's recent planning retreat for its new five-year plan.

It was hoped that the impact of the project would be the implementation of the project recommendations with legislative appropriation. To date, none of the white paper recommendations have been implemented. There has not been a formal evaluation of why the recommendations have not been implemented, but some of the possible reasons, are:

- Budget constraints in Florida due to reduced tourism revenue as a result of the Twin Towers terrorist attack, which occurred several months prior to the release of the white paper.
- Inadequate support among legislators.
- Inadequate legislative advocacy among the disability community and organized dentistry.
- Lack of an effective state-wide oral health advocacy organization to promote the white paper recommendations.
- Lack of information about the cost associated with each of the recommendations.
- Lack of sufficient details about how each of the recommendations would be implemented.

Budget Estimates and Formulas of the Practice:

The total budget for the project was $30,000, over a two year period. These funds were used to pay travel and lodging expenses for committee members who had to travel to the face-to-face meetings, teleconferences, clerical support, and to compensate the four white paper authors for the time spent on the project. The funding also allowed the major authors of the study to conduct research, convene committees, develop recommendations and write the report.

Lessons Learned and/or Plans for Improvement:

Lessons learned include:

1. When legislators or other very busy individuals are included on an advisory committee, they may find it difficult to attend meetings. Make a special effort to assure that they, their legislative assistant, or a designated representative can attend the meetings.
2. Consider the use of new computer software, such as, "GotoMeeting" to reduce travel expenses by conducting online conferences rather than face-to-face meetings.
3. Although the $30,000 funding the project was adequate to achieve all the project tasks, it should be considered the minimal amount required. A more reasonable funding level for a project of similar scope would be up to $40,000.
4. The two dental schools in the state authored the white paper; other groups such as disability organizations and family advocacy groups were included in the project but did not have an authorship role. In hindsight, the white paper might have garnered greater force or support if a wider range of allies had a full authorship role, rather than a more limited role as contributors.
5. In Florida, the state DD Council was to make the white paper recommendations their legislative priority, but the Council did not assemble a wide coalition of disability and oral heath advocates to work closely with them. In hindsight, it may have been more fruitful if they had worked more closely with other groups, such as the Florida Dental Association, the state wide oral health coalition and the Florida Voice on Mental Retardation, to have greater influence in the legislature.
6. Timing is everything. The loss of Florida's income stream secondary to the 911 terrorist attack occurred only a few months prior to the release of the white paper. It is likely that this unfortunate timing was a major factor that prevented the white paper recommendations from being considered.
7. The white paper did not include budget estimates to implement the recommendations because the report was considered a "first-step" only. The plan was to follow the white paper with a legislative budget request at a later date. In hindsight, there may be advantages to including financial information in the report itself, to provide a fuller picture of what it would require to implement the recommendations.
8. It is critical to establish, at the very beginning of the project, several legislator-advocates who are willing to champion the cause. And the more the merrier, because many of these folks don't get reelected or choose not to run again.
9. It is important to understand that state DD Councils typically have a number of committees and Task Forces that address specific areas of concern, e.g., health, transportation, employment, education, etc. To avoid misunderstandings about the scope or methodology of a DD Council-funded project, it is essential, before beginning work on a project, to discuss the proposed project with all of the committees and individuals that may have input into the process.

Plans for improvement include:

There are no plans at the present time to conduct additional studies related to the white paper, or to undertake any major initiatives to promote the adoption of the white paper recommendations.

Available Information Resources:

- **Access to Oral Health Care for Florida's Citizens with Developmental Disabilities.** Document prepared by: The University of Florida College of Dentistry and Nova Southeastern School of Dental Medicine. http://www.fddc.org/LINKS/pdf/AOHCfull.pdf or www.dental.ufl.edu/faculty/pburtner/scdlinks/AOHCfull2.pdf
- Florida Developmental Disabilities Council, Inc. Website: http://www.fddc.org/HOME/index.asp
- Special Care Dentistry Links: www.dental.ufl.edu/faculty/pburtner/scdlinks/

SECTION III: PRACTICE EVALUATION INFORMATION

Impact/Effectiveness

How has the practice demonstrated impact, applicability, and benefits to the oral health care and well-being of certain populations or communities (i.e., reference scientific evidence, outcomes of the practice and/or evaluation results)?

Positive outcomes of the white paper include: (1) Led to the DD Council funding educational seminars designed to inform dentists about the need for comprehensive care for Florida's citizens with DD and to provide clinical information about providing comprehensive dental care to individuals with DD; (2) Provided lawmakers, agency heads, educators and related organizations with data concerning the number of citizens residing in Florida who have developmental disabilities and their experiences at attempting obtain comprehensive oral health care from private dental practitioners; (3) Provided Florida with much of the information needed for writing the proposal in response to the Robert Wood Johnson Foundation Request for Proposals for the **State Action for Oral Health Access** grants in April 2002; and (4) Served as a benchmark or template for addressing access to oral health care for people with disabilities residing in other states. However, the adoption of the white paper recommendations has not occurred in Florida.

Efficiency

How has the practice demonstrated cost and resource efficiency where expenses are appropriate to benefits? How has the practice demonstrated realistic and reasonable staffing and time requirements? Provide unit cost analysis or cost-benefit analysis if appropriate.

The DD Council's decision to commission a white paper was based on the assumption that a $30,000 investment in creating the report might result in a legislative appropriation of many times that amount, to improve the oral health of people with disabilities. If this scenario unfolds successfully, then the expenditure of funds would be most cost-efficient. Because achieving legislative change is usually a long-term process, it is too early to determine if this white paper strategy is "efficient" or not.

In terms of the *process* of developing a white paper, the strategy of using existing faculty from the states' two dental schools is an efficient use of the state's resources. It would have been much more expensive to assemble a separate project staff or hire consultants for this project.

Demonstrated Sustainability

How has the practice showed sustainable benefits and/or how has the practice been sustainable within populations/communities and between states/territories? What mechanisms have been built into the practice to assure sustainability?

The white paper was funded as a one-time effort. From that perspective it is not a "sustainable" activity.

Collaboration/Integration

How has the practice built effective partnerships/collaborations among various organizations and integrated oral health with other health projects and issues? What are the traditional, non-traditional, public and private partnerships/collaborations established by the practice for integration, effectiveness, efficiency and sustainability?

The process of developing the white paper included the collaboration of key stakeholders who have a common interest in the oral health of people with disabilities. These stakeholders leveraged their resources for an integrated effort. Stakeholders include:

- The Florida DD Council funded the project and input from the Council's Health Care and Community Living task forces (as well as numerous other professionals in the field) was obtained.
- The University of Florida School of Dentistry and Nova Southeastern University School of Dental Medicine provided expertise and collected data, conducted analysis, and prepared the white paper.

- Additional individuals, agencies and organizations representing and advocating for persons with developmental disabilities provided their input and perspectives to potential solutions and proposed recommendations including:
    - Individuals with developmental disabilities
    - Gulf Coast Autism Association, Inc.
    - Florida Dental Association
    - Florida Dental Hygiene Association
    - Florida's Voice on Mental Retardation
    - Medicaid Program Development, Florida Agency for Health Care Administration
    - Children's Services Board of Broward County
    - Health Care & Prevention, Florida Developmental Disabilities Council
    - Florida Hospital Association.
    - Department of Pediatric Dentistry, University of Florida College of Dentistry
    - Department of Community Dentistry, Nova Southeastern University College of Dental Medicine

Objectives/Rationale

How has the practice addressed HP 2010 objectives, met the call to action by the Surgeon General's Report on Oral Health, and/or built basic infrastructure and capacity for state/territorial oral health programs?

The white paper is a first step in Florida for advancing the Healthy People 2010 Objective 6-10, to increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

The paper supports a response to the Surgeon General's Call to Action to Promote Oral Health to

- Implement strategies to overcome barriers in oral health disparities need to engage all groups, particularly those most vulnerable, in the development of oral health care programs that work to eliminate health disparities and aim to Identify and reduce disease and disability as well as improve access to oral health care
- Increase Oral Health Workforce Diversity, Capacity, and Flexibility to Meet Patient Needs.

Extent of Use Among States

Describe the extent of the practice or aspects of the practice used in other states?

Several states have developed reports that serve as white papers:

- Massachusetts
  Center for Developmental Disabilities Evaluation and Research; Eunice Kennedy Shriver Center, University of Massachusetts Medical School (prepared for the MA Department of Mental Retardation, Oral Health Workgroup). **A Review of Models to Improve Dental Services for Adults with Mental Retardation: A Look Outside Massachusetts.** June 2005. (http://www.umassmed.edu/cdder/)
- California
  California Statewide Task Force on Oral Health for People with Special Needs. **Statewide Task Force Recommendations for Improving Oral Healthcare for People with Special Needs.** (http://www.pacificspecialcare.org/task_force.htm)
- North Carolina
  Sims T, Robarge A. **Consortium for the Development of Community Supports: Dental Survey Report 2003.**