2011 Report:
Oral Healthcare for Adults with Developmental Disabilities in Arizona

ARIZONA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL℠

SUBMITTED TO:

ARIZONA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

SUBMITTED BY:

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Abstract

In December, 2010, the Arizona Developmental Disabilities Planning Council (ADDPC) issued a request for proposal for an external firm to perform an update of the 2006 Report "Providing Oral Health Care for Adults with developmental disabilities" for the ADDPC. The purpose of the 2011 project, according to the Scope of Work, was to fulfill 2011 public policy and legislative priorities identified by ADDPC.

The research methods employed for purposes of addressing the areas under study involved the development of a survey for gathering primary data from a sample of Arizona-based adult consumers with developmental disabilities. A sample of 10% of adults with developmental disabilities was selected from the population reported by the Arizona Department of Economic Security, Division of Developmental Disabilities, as of May, 2011. The total sample obtained for the report consisted of 466 consumer surveys, 456 of them in English, and 10 in Spanish, received by the researcher. 436 total surveys were complete and usable for purposes of the analysis.

Following the administration and collection of the consumer survey, the dental team and other stakeholder interviews and focus groups, as well as the review of the literature, the researcher performed both quantitative and qualitative analyses of the data for purposes of synthesizing findings and identifying conclusions and recommendations. Extensive demographic information was obtained regarding participants: their level of education, income, insurance coverage, living situation, personal oral health care needs, care practices, description of health conditions, and patterns of prevention, treatment, and obstacles to receiving care and treatment.

Strategic Approach for Recommendations

1. Incorporate a version of a best practice recognized by the Center for Disease Control (2008), in systematic oral health surveillance, such as that of the North Dakota Oral Health Surveillance Program.
2. Initiate a statewide program of caregiver training, such as that described by Glassman (2006) in the State of Florida, incorporating coaching of caregivers, and systematic re-training on a periodic basis, to address employee turnover.
3. Build a statewide campaign to create awareness, disseminate knowledge, and clarify the extent of need.
4. Develop an accurate and comprehensive database documenting a "clean and screen" campaign.
5. Formulate and maintain periodic updates of a complementary database of capacity (dentists available to deliver services as part of a highly publicized, concerted campaign).
6. Simplify delivery of initial, baseline services, consisting of (a) Diagnostic screening, (b) Cleaning of teeth, and (c) Caregiver training and support materials, to serve all adult Arizonans with developmental disabilities.
7. Provide fiscal and non-fiscal incentives to dental professionals, contributors, caregivers, and adult consumers themselves. Possible incentives might include, but not be limited to, tax incentives and professional recognition for dental professionals, adjusted insurance fees for proactive care, and awards for purchasing goods and services for caregivers.
8. Actively pursue an innovative initiative in response to segments of (2010) "The Patient Protection and Affordable Care Act," to formalize training and capacity in Arizona for growing the field of dentistry for adults with developmental disabilities.
9. Identify and develop opportunities to share with elected officials and other government leaders the importance of oral healthcare as a way of maintaining health and well-being, especially for citizens with developmental disabilities.
10. Establish an alternative stream of support, in the form of supporting foundation grants, community, business, and individual funding through tax-free opportunities that result in long-range, sustainable oral healthcare to adults 18 years of age and older.
11. Develop a support, reform and action commission composed of dental professionals, caregivers, and consumers to support oral healthcare for Arizonans with developmental disabilities.

Supporting Tactical Methods for Recommendations

1. Build capacity through opportunities specified in the (2010) Patient Protection and Affordable Care Act, specifically the establishment of a consortium of providers for special needs/special care dentistry, training for caregivers, and establishing a major presence in the Oral Healthcare arena in the form of a public-private partnership established to deliver a state-of-the-art care to the population of individuals with developmental disabilities.

2. Apply the Thomas F. Gilbert (2007) Model of Human Performance Engineering to address gaps in Knowledge, Instrumentation, and Motivation, and establish community-specific models that address this significant need.

3. Build and award recognition and funding for replicable, community-based models contributing to the ongoing pursuits of simplified implementation of models for sustainability of oral health care baseline services in a wide range of community types.

The recommendations in the following section are based upon strategic, system- and process-level change. Employing the Gilbert (2007) Model of Human Performance Engineering recommendations calls for proactive change in Knowledge (through training and education), Instrumentation (through tools), and Motivation (through incentives), as shown in Chart 149.

Recommendations

Chart 149: Model of Human Performance Technology

Knowledge Deficit	Instrumentation Deficit	Motivation Deficit
Can be addressed by	*Can be addressed by*	*Can be addressed by:*
Training and Education	Tools and Instruments	Incentives (monetary and/or non-monetary)

Address Gaps in Knowledge

Gilbert's Human Performance Engineering Model suggests that gaps in knowledge are best addressed by providing training and education. There has long existed a division between the fields of medicine and dentistry. That oral healthcare is the "gateway" to effective general health, is a little known fact. To address this particular gap in knowledge, the following recommendations are provided.

Establish a major, statewide awareness campaign that clarifies the link between Oral Healthcare and general health, targeting adults with developmental disabilities, using a specific timeline, through the following specific components:

a. High profile task force with a mission to simplify and amplify the message.

b. Integration of business, government, and community leaders identifying individuals who can lend visibility and support, as well as persons whose families share a commitment to serving persons with developmental disabilities.

c. Relationship among structured subcommittees representing small, medium, and large communities, and urban, suburban, and rural communities and their unique needs.

d. Documentation of need, and corollary resource base, encompassing capacity in medical/dental resources, funding support from service organizations, foundations, and individual participation in a community-based structure.

e. Event-based, measured timeline that identifies milestones along a specified path that is project-managed.

f. Public relations campaign that features newsworthy articles, radio and television publicity, internet-based and social network-driven communiqués, and integrated messages to local, county, and state government personnel and elected officials.

g. Training materials for caregivers, family members, and adult consumers, to support accurate, easy instruction on prevention and care for oral health.

Address Gaps in Instrumentation

Gilbert's Human Performance Engineering Model suggests that gaps in Instrumentation are best addressed by providing tools that make delivery of services possible, or even probable. In this instance, instrumentation encompasses a wide range of elements associated with technical delivery of services.

It should be noted that funding of instrumentation-related elements specified below remains an issue, but must not be overlooked when specifying gaps in the system and the need to plan a response to such elements.

Support the awareness and database campaign through the provision of applicable technology for serving the oral healthcare needs of adults with developmental disabilities, through each of the following components:

a. Assistive technology to facilitate supportive dental treatment for individuals with developmental disabilities. The distribution of mechanical toothbrushes, flossers, and instructional materials that clarify simple methods of preventing problems with teeth.

b. Service delivery hardware, software, and transport units, including mobile dental service units, tele-dentistry mechanisms that aid in delivering streamlined forms of diagnosis and treatment, to reduce the mileage for families needing care for individual adult consumers.

c. Easy-to-use whiteboard-based checklists for use, where appropriate, to facilitate care and follow-through for adult consumers and caregivers.

Address Gaps in Motivation, Including Funding

Gilbert's Human Performance Engineering Model suggests that gaps in Motivation are best addressed by providing incentives (monetary or non-monetary, as the situation dictates) that encourages, induces, and/or inspires people to pursue courses of action that contribute to the performance objective of cleaning and screening every adult consumer in Arizona who has developmental disabilities.

Stimulate desirable and necessary participation in the long-range campaign by providing monetary and non-monetary incentives to dentists, dental hygienists, caregivers, and adult consumers, through:

a. Development of a fee share program that facilitates contributions by non-dental contributors, to supplement the delivery of services by oral healthcare professionals.

b. Establishment of one or more non-profit organizations, as appropriate, to gather funding from foundations, service organizations, and individuals, for purposes of ensuring systematic oral healthcare prevention and treatment for adults with developmental disabilities.

c. Funding mechanisms through structured support, utilizing: foundation grants, service organization funding, and individual funding support, both large-scale and small-scale/incremental contributions, to support a focused, campaign style baseline "Clean and Screen" initiative that demonstrates and helps build a baseline of care in communities statewide.

d. Establish mechanisms for citizen and organizational contributions to dental care, rather than relegating all responsibility for fee reduction and service donation to dentists.

e. Proper third-party coding of services that leads to proper and timely monetary compensation, accurately reflective of the services delivered in terms of actual time and associated costs of providing prevention and treatment.

f. Support of opportunities to build the dental practice of participating professionals, in association with services delivered to the population of patients having developmental disabilities.

g. Structured reward systems that fund the development of post-graduate specialties in dentistry that serves individuals with developmental disabilities.

h. Systematic, competitive rewards for caregivers and adult consumers in return for engaging in, documenting, and demonstrating results of prevention, based upon oral healthcare practices taught statewide. Rewards for prevention would be one method of rewarding patients for avoidance of health challenges based in part upon neglect of oral health.

i. Statewide recognition of donor organizations [notably, individual contributors, service organizations, non-profit organizations, and foundations] for contributing to prevention or "clean and screen" endeavors.

j. Organized, well-publicized, event-based campaigns for prevention that begins with adult consumers with developmental disabilities and eventually expands to general population of the State. (The reverse of the usual pattern, whereby a reduced version of a larger, more effective campaign is imitated for the developmental disabilities communities, rather than initiating the campaign with their needs specifically emphasized.)

k. Enlisting dental practitioners, including dentists and dental hygienists, to participate in a service campaign to screen patients on specific dates across the state to gain data on adults with developmental disabilities.

l. Documented formulation of regional and local database specifying oral healthcare need, provider care, and community support.

m. Development of multiple specific community-based models that demonstrate potential for continuation and replication in communities having similar composition and capacity.

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Purpose of Report

In December, 2010, the Arizona Developmental Disabilities Planning Council (ADDPC) issued a request for proposal for an external firm to perform an update of the 2006 Report "Providing Oral Health Care for Adults with Developmental Disabilities" for the Arizona Governor's Council on Developmental Disabilities. The purpose of the 2011 project, according to the Scope of Work, was to fulfill 2011 public policy and legislative priorities identified by ADDPC.

The purpose of ADDPC is authorized under Subtitle B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act, Public Law 106-402). That purpose is "to engage in advocacy, capacity building and systemic change activities that contribute to and assure that a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated in all facets of community life." [Developmental Disabilities Act, Section 121(1-2)].

This study is consistent with the 2007-2011 Objective #2 Health Care Goal of the Council, specifying that "Individuals with developmental disabilities will have access to and use of coordinated health, dental, behavioral health and other human and social services, including prevention activities, in their communities."
The study further supports the current goals for 2011-2016 established by the ADDPC, entailing within Goal 1, a "broaderrange of choice" for the proposed "alliance of various self-advocacy groups within Arizona;" and entailing within Goal 3 "increased and improved access to reliable and current information to make well informed decisions." Oral healthcare is essential for the achievement of Goal #3.

For this study, ADDPC sought to describe the current environment and the status of access to dental care available to persons with developmental disabilities and to identify opportunities for enhancement as deemed worthy of consideration.

The ADDPC has established that this study shall observe the definition of developmental disabilities as found within Public Law 106-402, also known as "The Developmental Disabilities Assistance and Bill of Rights Act of 2000." The Council defines Developmental Disability as:

> a severe, chronic disability of an individual that a) is attributable to a mental or physical impairment or combination of mental and physical impairments; b) is manifested before the individual attains age twenty-two; c) is likely to continue indefinitely; d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and, economic self-sufficiency; and, e) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Specific deliverables established for research included the following:

Written Project Plan A written plan, inclusive of milestones throughout the duration of the project, addressing all specified areas of the report, was submitted to ADDPC staff and utilized as a guide to ensure comprehensive elements required to perform the study. Monthly reports, face-to-face or telephone meetings, and written summaries were provided to ADDPC.

Online and Paper Data Questionnaire A survey for completion by adult consumers with developmental disabilities was drafted based upon specified information sought for the survey, in addition to established questions in the national literature. (See Appendix A.)

Interview and Focus Group Protocols Interview protocols were drafted and reviewed with ADDPC, for the purpose of optimizing information from stakeholders associated with adults with developmental disabilities; families and caregivers of adults with developmental disabilities; and dental team members associated with Special Needs Dentistry. The resulting three interview protocols were finalized in February, 2011. (See Appendix B.)

Demographic Statistics Information pertaining to population density of persons with developmental disabilities by county, city, major urban area (Phoenix, Tucson, and Flagstaff), as well as age distribution of consumers, was identified. (See Demographic section of report.)

Summary Data on Eligibility and Service Information regarding eligibility for and receiving benefits from the Arizona Healthcare Cost Containment System (AHCCCS) was obtained, in addition to summary data on those individuals ineligible for AHCCCS benefits. In addition, the number of individuals eligible for other benefit plans, including private insurance, was examined. The scope of benefits services that cover or do not cover oral healthcare was also included in the summary.

Summary Data on Chronic Health Conditions A review of statistics indicating health conditions by type and rate that contribute to or result in the development of oral or dental health disease was examined. (See Demographic section of report.)

Frequently Prescribed Medications and their Impact on Oral Health A review of the literature regarding the effects of frequently prescribed medications and their effects on the oral healthcare of adults with developmental disabilities, was provided. (See Review of the Literature.)

Cost Data of Typical Dental Services by Arizona County Cost data were obtained for typical dental services on a per-county basis for the State of Arizona, based upon sampling of each county. A specified range of costs per service was obtained. (See Cost Section of Report.)

Context of 2011 Report

The timing of the 2011 report of Oral Healthcare for adults in Arizona with Developmental Disabilities follows the elimination in of all dental care benefits for individuals 21 years and older, effective October, 2010. As a result, several pertinent issues have emerged: (1) Consumers' concern about how to meet their oral healthcare needs, (2) Dental practitioners' needs for serving the adult population of consumers, given the absence of public funding, (3) Stakeholders' recognition of the necessity of establishing systems of service, and (4) Recognition by the general public of the relationship between oral health and overall physical health.

Overview of Report

In fulfillment of the Scope of Work specified by ADDPC for the 2011 Report, six different overall areas were developed:

1. A review of the literature emphasized identification of the oral conditions and characteristics frequently found in consumers with developmental disabilities. Prevention efforts were specified based upon recommendations by professional dental teams nationwide (Special Care Dentistry Association website, 2011). The special care dentistry was described, in terms of its approach to the challenge of serving the population in the most beneficial manner. A spectrum of response by dental professionals was included. The state of public funding at the national level was explored, showing a state-by-state comparison. Current approaches to examining the challenge were identified, emphasizing trends, issues and opportunities for serving adults with developmental disabilities.

2. Demographic and eligibility-for-service information A point-in-time summary of population statistics for adult consumers with developmental disabilities in Arizona was included, by major urban area, by county, by age, and by ethnic distribution. Health conditions and medication information were examined, in addition to the span of coverage and non-coverage of oral healthcare.

3. Professional perspectives on dental care for the population under study were summarized, based upon interviews and focus groups of dental teams. Interview and focus group information emphasized training in dentistry; current service levels for the population by professional interviewees; perceived system-level issues and opportunities specified by dental professionals; and perspectives on the efficacy of trends in addressing dental care for adults with developmental disabilities.

4. Professional perspectives on dental care by other stakeholders provided ideas and suggestions from state policy makers, agencies and organizations associated with adults who have developmental disabilities, direct care providers and health care professionals. Summary views were provided for the purpose of ensuring direct practical value and system-level opportunities.

5. Consumer and family perspectives comprised a major emphasis of this report, with direct information relative to obstacles and barriers associated with treatment, including but not limited to proximity to services; availability of general dental practices; availability of special needs dentistry; transportation and behavioral issues. Further perspectives were summarized for funding of preventive and treatment programs, and concerns regarding the delivery of oral healthcare services in residential living. Such issues as waiting lists, costs of services, unmet oral healthcare needs, alternatives to service undertaken by consumers, and personal narratives were also emphasized.

6. Conclusions and Recommendations The 2011 Study culminated in conclusions based upon the findings of the study, identifying patterns and opportunities. Recommendations based upon strategies and tactics for addressing the challenges cited by consumers and stakeholders were made. In addition, issues and trends from the literature were examined for potential action, based upon current gaps in knowledge, instrumentation, and motivation deemed by the research team to be inherent in the present system.

Methodology for Study

Research Methods: Consumer Survey

The research methods employed for purposes of addressing the areas under study involved the development of a survey for gathering primary data from a sample of Arizona-based adult consumers with developmental disabilities. Successive drafts of the survey were circulated for input and advisement to representatives of multiple agencies, including but not limited, to the following in Arizona:

- Arizona Developmental Disabilities Planning Council
- Arizona Dental Foundation
- Arizona Health Care Cost Containment System
- Arizona Department of Economic Security, Division of Developmental Disabilities
- Arizona Department of Health Services
- Arizona Dental Association
- A.T. Still Dental School
- Maricopa County Oral Health Leaders, Advocates, & Resources (MOLAR)
- Arizona Governor's Advisory Council on Aging, Social, Health, and Alzheimer's Committee (SHAC); Oral Health Committee
- Arizona Association of Providers for People with Disabilities
- Gompers Habilitation Center Dental Program
- Arizona Special Olympics
- United Healthcare

The survey was piloted with six families by the Arizona Department of Health Services (ADHS) Office for Children with Special Health Care Needs, and was revised accordingly, for optimal item clarity, comprehensiveness and specificity. The survey was finalized and prepared for distribution in April, 2011. As noted, a copy of the survey is included in Appendix B.

The Arizona Department of Economic Security, Division of Developmental Disabilities (ADES, DDD) assisted the study team in providing a sample of 10% of adults with developmental disabilities May, 2011. On June 3, 2011, a cover letter and survey, in both English and Spanish languages, was sent through ADES, DDD to a sample of 1,176 Arizona consumers. The letter, printed on ADDPC letterhead, was sent by the Executive Director and the researcher, along with a stamped, return envelope to the researcher. Consumers were advised that they could take the survey either in printed form and return it by mail, or that they could take the survey either in English or in Spanish online, through the link provided on the cover letter. The letter further specified that survey responses (1) were anonymous, (2) would be compiled with no individual identifying information, and (3) would in no way affect services of consumers from the Division of Developmental Disabilities. The response to the survey was 23.9%, representing 281 surveys received.

Given the goal of reflecting the needs of a broad range of adult consumers, the research team utilized the procedure of snowball sampling, using a referral mechanism for gaining input from difficult-to-reach participants, including Native American communities and those individuals not on the rolls of the Division of Developmental Disabilities. Several agencies that serve adult consumers with developmental disabilities were contacted and asked to encourage responses from targeted sub-populations of interest. Notification of the survey was posted on multiple websites associated with Arizona consumers having developmental disabilities, including Arizona Special Olympics, Arizona Department of Health Services, and related sites. 185 responses were received through the referral sample. The total sample obtained for the report consisted of 466 consumer surveys, 456 of them in English, and 10 in Spanish, received by the researcher. As of July 21, 2011, 22 additional surveys arrived by mail, and were too late to be included in the analysis.

Statistical Procedures

For purposes of survey analysis, descriptive statistics were (e.g. frequency distributions) to describe all survey items. In addition, to assess relationships between age and oral healthcare items, Spearman's rank correlation was used. For relationships between gender and oral healthcare items, chi-square or correlation was used.

For relationships or differences between source of income and oral healthcare items, chi-square or analysis of variance (ANOVA) were used. Dental insurance differences in association with oral healthcare, were examined, using chi-square.

Relationships between level of independence of participants' care of teeth and oral healthcare items were assessed with Spearman's rank correlations.

Relationships between total number of dental problems and oral healthcare items were assessed with Spearman's rank correlations. Additionally, relationships between total number of dental problems over the past 6 months were also assessed with Spearman's rank-order correlations.
As a side note, a large number of statistical tests were examined in this report, inflating the Type 1 error rate above the widely accepted .05 level. Thus, a Bonferonni correction was performed, the new p value is $p < .0001$ for a test to be considered statistically significant.

The effect sizes, and not solely p-values, should be noted when interpreting the results. For correlations, a correlation of .10 is considered a small effect, .30 a medium effect, and .50 or greater a large effect (Cohen, 1988). In terms of the gender differences, the odds ratios can serve as a measure of how big the difference is between groups.

Research Methods: Interviews and Focus Groups

The researcher worked with ADDPC to identify potential stakeholders representing Arizona government officials and agency representatives, beginning with membership on the ADDPC and membership on SHAC; Oral Healthcare Subcommittee. During the initial week of the project, the researcher participated in the Oral Healthcare Subcommittee meeting, and began making connections with relevant stakeholders. A referral method was pursued, whereby likely stakeholders recommended other individuals who would represent policy and service professionals relevant to the project. In addition, the researcher made presentations to multiple organizational meetings for the purpose of stimulating interest in and suggestions for the study, including persons who would be instrumental in guiding content and approach.

Dental professionals were identified through organizational stakeholders, lists of dentists serving adults with developmental disabilities, and University-referrals, for purposes of assembling a list of individuals to interview. The researcher's attendance at conferences, meetings, and training sessions, further facilitated the identification of individuals to interview for the study.

Analysis of Data

Following administration and collection of the consumer survey, interviews and focus groups with dental teams and other stakeholders, as well as the review of the literature, the researcher performed both quantitative and qualitative analyses of the data for purposes of synthesizing findings and identifying conclusions and recommendations.

Both statistical summaries and keyword-based taxonomic information were derived from the extensive analysis of stakeholder and dental professional input. The combined information was prepared for exploration of actionable approaches to improving the challenges articulated in the study.

An emergent taxonomic analysis, developed by Murphy (2011), was utilized for all open-ended responses in the consumer survey. The procedure is summarized below:

1. Reviewed all open-ended responses, consisting of unprompted input of a general nature.
2. Responses were grouped into emergent classifications, based upon language and concept provided by respondents.
3. Clustered categorical information by category.
4. Quantified content according to number and percentage of all responses received.
5. Examined quantitative and qualitative information, for purposes of enhancing understanding of consumer input.

Identification of Trends, Issues, and Opportunities

A framework for analysis of the trends, issues and opportunities identified from the study was derived from Gilbert (1996), using a model for system-level analysis of change opportunity, given specified gaps in knowledge, instrumentation and motivation. The research team identified strategic and supporting tactical approaches for consideration by ADDPC as it considers possible approaches to serving the oral healthcare needs of adult individuals with developmental disabilities.

Activities in Support of Project Deliverables

For purposes of conducting the study, the following activities were undertaken, in support of the project deliverables:

Review of the Literature

1. Reviewed H.R. 3590: Patient Protection and Affordable Care Act.
2. Reviewed special needs dentistry training documentation from Arizona Dental Foundation.
3. Conducted successive reviews of the literature, based upon recommendations from experts in oral healthcare for special needs populations at the national, regional, and state levels.
4. Performed review of the literature for examination of pertinent studies for purposes of constructing the instrument for consumers.

Interviews and Focus Groups

5. Toured North Country Healthcare Dental Program in Flagstaff and interviewed 5 dentists and 2 dental hygienists.
6. Interviewed 30 stakeholders and caregivers, both individually, and as part of focus groups, for purposes of gaining multiple perspectives relative to issues, accessibility, funding, and oral healthcare practices associated with adults with developmental disabilities.
7. Conducted one-on-one interviews with 15 dentists and 5 dental hygienists for purposes of identifying key issues associated with the practice of special needs dentistry.
8. Conducted 2 focus groups with 19 dentists engaged in the June, 2011 training program in special needs dentistry, sponsored by the Arizona Dental Foundation.
9. Interviewed national representative of the American Dental Association.
10. Scheduled and conducted multiple face-to-face meetings with stakeholders of oral healthcare for adults with developmental disabilities.
11. Interviewed individual ADDPC staff.

Facility Tours

12. Toured A.T. Still Dental University and received overview from Director.
13. Toured Gompers Dental Program and received overview from Director and resident dentist
14. Toured North Country HealthCare Dental Clinic and received overview from Director.

Attendance at Conferences and Meetings

15. Participated in multiple planning and update meetings with ADDPC Leadership and staff.
16. Attended the Arizona Governor's Advisory Council on Aging SHAC; Oral Healthcare meeting.
17. Solicited interviews at Arizona Special Olympics event at Mesa Community College during April, 2011 games.

18. Worked the ADDPC exhibit display with Executive Director of ADDPC at the 2nd Annual 2011 Disability Empowerment Center Health & Wellness Fair.
19. Attended Indian Health Summit presentation on Tele-dentistry and interviewed Northern Arizona University representative and other dental team professionals prior to the presentation.

Presentations

20. Presented to quarterly meeting of Gompers Habilitation Centers Parents and families to stimulate interest in interviews.
21. Presented to Arizona Association of Providers for People with Disabilities (AAPPD).
22. Presented to Goldensun Board of Directors.
23. Presented summary of oral healthcare study plan to the Grants Standing Committee of the Arizona Developmental Disabilities Planning Council.
24. Participated in and presented to Maricopa County Oral Health Leaders and Advocates (MOLAR) Work Group Meeting.
25. Presented to Pima County Health Department regular meeting of the Oral Healthcare Provider group in April.
26. Presented to Statewide meeting of Nursing Coordinators for Department of Developmental Disabilities.

Project Documentation

27. Drafted, reviewed, and updated the Project Plan in successive discussions with ADDPC staff.
28. Conducted monthly meetings with Executive Director of ADDPC during project.

Scope of the Issue: Review of the Literature of Oral Healthcare for Adults with Developmental Disabilities

Oral Conditions and Characteristics Often Found in Adults with Developmental Disabilities

Farsai and Calabrese (2002) have specified oral conditions and characteristics often found in adults with developmental disabilities, indicating the following primary concerns:

The authors note the danger of, xerostomia, or "dry mouth" that deprives the human system of the needed secretion of saliva to maintain health, reduce bacteria, while moistening tissue and building tooth enamel. Medications frequently prescribed for treatment of high blood pressure, heart disease, diabetes, allergies, depression and many other conditions reportedly results in xerostomia.

The authors further indicate that food debris and bacteria left in the mouth, combined with a diet of high sugar intake, can contribute to tooth decay. Decayed roots, gum recession and/or bone loss can lead to decay on the surface of teeth. Absent correct oral hygiene, patients are more vulnerable to cavities and gum disease. Such gingivitis can lead to the loss of teeth, caused most commonly by "advanced tooth decay, advanced periodontal disease, and trauma from falls or accidents." The replacement of missing teeth can strengthen the individual's ability to chew food, in addition to enhancing personal appearance, both of which improve quality of life, according to Farsai and Calabrese (2002).

Halitosis ("bad breath") can be caused by a number of factors, often resulting from upper respiratory conditions. The buildup of mucous, infections, ineffective digestion can result in this condition. Inadequate oral hygiene, large cavities, or periodontitis can also be signaled by the condition of halitosis.

Other extreme patterns of food processing, including "pouching" of food particles and medication can pose dental challenges, as well as malnutrition. Regurgitation (rumination) is often present with individuals with cognitive disabilities. Food is swallowed, then regurgitated with stomach fluids and acids. Severe indigestion and malnutrition can result.

The literature provides information about probable dental conditions that are present for individuals who have developmental disabilities. According to the National Institute of Dental and Craniofacial Research (2008), "Data indicate that people with intellectual disability have more untreated caries (cavities) and higher prevalence of gingivitis and other periodontal diseases than the general population." Among the factors that exacerbate dental challenges are consumers' inability to care for brushing and flossing without assistance, as well as consumers' use of medications that may lead to gingival hyperplasia. Untreated cavities, drinking sugary beverages, and taking medications that cause xerostomia (dry mouth) without drinking sufficient water, may lead to dental problems. ***Individuals with intellectual disability generally show a higher probability than those in the general population for "missing permanent teeth, delayed eruption, and enamel hypoplasia." (National Institute, 2008)***

According to the National Institute, bruxism (clenching or grinding the teeth), mouth breathing, tongue thrusting, and self-injurious behavior, such as biting the lips or eating inedible substances, can further lead to harm to the oral health. Also more probable for people with limited cognitive ability are trauma and injury due to falling, other accidents, or abuse. (National Institute, 2008)

According to Stiefel (2002), individuals with cerebral palsy commonly have poor oral hygiene and ineffective patterns of oral hygiene due to medications prescribed for their motor conditions. This situation, combined with insufficient water intake, possible mouth breathing, and the effects of medications, inclusion of sugar in medications and the diet, as well as undesirable practices such as food pouching, can add to the challenges to oral health. Further, severe bruxism, tooth wear, damage to temporomandibular joint, and swallowing problems, result in deleterious situations regarding oral health. (Stiefel, 2002).

Further challenges include malocclusion that may derive from a musculoskeletal problem, including protruding anterior teeth, and resultant drooling. Dysphagia, or difficulty swallowing, means that food may remain in the mouth longer than it does in people without developmental disabilities. Stiefel (2002) further notes that for patients with cerebral palsy, “Coughing, gagging, choking, and aspiration are related concerns.” Drooling, hypotonia, and the ability to close the mouth, in addition to bruxism, which can lead to the wearing down of teeth, present further difficulties. Hyperactive bite and gag reflexes, and trauma and injury are further challenges.

Health Conditions and Medications

Individuals with developmental disabilities typically have been prescribed medication for the purpose of mitigating symptoms that interfere with health or quality of life. Many of these medications have contributed to additional symptoms that affect oral healthcare. In Chart 1, several frequently occurring side effects related to prescription medications are noted. The presence of these additional threats to patients with developmental disabilities represent additional considerations for self-advocates, families, and other caregivers.

As noted in Table 1, Xerostoma, or “Dry Mouth” can result from the use of antihistamines and other drugs. A resultant decrease in saliva can lead to inflammation of soft tissue, pain and infection. Chronic dry mouth can create tooth decay, as well as problems for denture wearers.

Inflammation, including mouth sores, frequently occur in the presence of high blood pressure medications, oral contraceptives, immunosuppressive medications, and some chemotherapy medications.

“Gingival Hyperplasia,” or gum tissue overgrowth, often occurs in association with anti-seizure medications, as well as immunosupressant drugs taken by organ transplant patients, and calcium channel blockers taken by heart patients. Only if extremely careful oral hygiene begins before or during the initial medication, can gum tissue overgrowth be controlled. The tissue overgrowth itself can make oral hygiene additional complicated, sometimes leading to gingivectomy (the removal of excess tissue).

Tooth discoloration, including oral sores or discoloration of soft tissue can result from taking medications given for blood pressure, immunosuppressive agents, oral contraceptives, and certain chemotherapeutic agents.

Abnormal bleeding can result from taking aspirin and prescribed anticoagulants, such as heparin or warfarin. These medications are prescribed to treat strokes or heart disease, but can cause bleeding problems during oral surgery or periodontal treatment.

Oral yeast infection, or “thrush,” can be the result of antibiotic and steroid drugs.
The death of bone tissue, is an additionally common side effect of medications given for individuals being treated for cancer or medications to assist in preventing or treating osteoporosis.

Chart 1: Oral Health Conditions and Associated Medications

Side Effect	Medications
Xerostoma (“Dry Mouth”) – Saliva, needed to clean the mouth, may be decreased by these medications, potentially leading to tooth decay and infection.	Tricyclic antidepressants
	Antihistamines
	Diuretics
	Anti-anxiety drugs
	Muscle relaxants
	Bronchodilators
	Narcotic painkillers
	Decongestants
	High blood pressure medications
	Sedatives
	Pain medications
	Antacids
Inflammation / Mouth Sores	High blood pressure medications
	Oral contraceptives
	Immunosuppressive agents
	Selected chemotherapy medications
Gingival Hyperplasia (“Overgrowth of Gum Tissue”)	Cyclosporine
	Anti-Seizure medication
	Calcium-channel blockers
Tooth Discoloration / Staining of Teeth	Anti-seizure medication
	Calcium-channel blockers
	Antimalarial drugs
	Tetracycline (taken in childhood when teeth are developing)
	Chlorhexidine
Abnormal Bleeding (During Surgery)	Aspirin
	Anticoagulants
Oral Yeast Infection (Thrush)	Antibiotics and steroid drugs combined
Death of Bone Tissue	Bisphosphonates used intravenously in cancer treatment
	Oral bisphosphonates for osteoporosis prevention and treatment

Prevention Specifications by Dental Professionals

The Surgeon General's report (2000) "Oral Health in America" brought to the public's attention the essential nature of oral health and its relationship to overall health in the human system. ***The report introduced the phrase, "silent epidemic," to refer to dental and oral diseases in the nation.***

The Florida State Oral Health Improvement Program (SOHIP) Working Group Report (2007) established the issue of extreme need of prevention in the following passage:

> *Patients with special needs frequently experience orofacial pain and discomfort. Oral conditions commonly observed in this special population include: chronic toothaches from decayed teeth; missing and loose teeth; chipped and fractured teeth; loss of supporting bone structure; dental abscesses; malocclusion and misaligned teeth; and, compromised esthetics due to missing anterior teeth. Parents report that when oral health care is not provided, these individuals suffer from seizures, malocclusions, tooth grinding and pain evidenced by grimacing. Oral diseases may have a detrimental effect on an individual's self-esteem, social interaction, education, career achievement, emotional state, and general systemic health. Clearly, poor oral health can and does have a significant negative impact on a person's health and quality of life.*

Dentists have advocated for prevention efforts at the personal, caregiving, and professional levels, placing particular emphasis on the care of adult individuals with developmental disabilities. The National Institute of Dental and Craniofacial Research at the National Institutes of Health (April 2008) has prepared a clear and understandable pamphlet titled "Dental Care Every Day: A Caregiver's Guide." This simple, step-wise set of instructions is designed to clarify for caregivers the simple steps that comprise an investment in oral healthcare of individuals who are unable to provide oral healthcare for themselves. Simple steps are made explicit. (1) Brush every day. (2) Floss every day. (3) Visit a dentist regularly. Sub-steps are provided in the 9-page booklet, indicating precisely how to execute each of the three specified steps. The booklet represents a clear and practical guide for caregivers and families, as well as for consumers who are able to care for their own preventive dental health.

Arizona Maternal Child Health Needs Assessment (2010). Arizona Department of Health Services established a key priority (#6): "Improve the Oral Health of Arizonans, indicating that 31% of Arizonans ages 2-5 had untreated tooth delay, compared to 16% of this age group at the national level." Anticipated positive changes cited by the study included: (1) Improvement of oral health through Health Resources and Services Administration (HRSA) oral health workforce grant, to establish sites for tele-dentistry, (2) Increased funding for Arizona First Things First for oral health needs of young children, and (3) Possible funding from the Affordable Care Act for infrastructure at the state level, as well as sealants through the schools.

Special Needs Dentistry

Special Needs Dentistry (SND), also known as Special Care Dentistry, as defined by the Special Care Dentistry Association, is "that branch of dentistry that provides oral care services for people with physical, medical, developmental, or cognitive conditions which limit their ability to receive routine dental care." (Special Care Dentistry Association website, 2011).

Where treatment requires accommodation, based upon physical, mental or medical situations, SND is needed. Service to adults with developmental disabilities can be placed in this category. Typically, movement disorders, mental or emotional challenges, necessitate care by a knowledgeable dental professional who correctly anticipates and is prepared by knowledge, instrumentation, and motivation to treat the patient. (Stiefel, 2002.) Use of the least restrictive approach is encouraged further by Romer (2009), as is the assurance of proper consent protocol.

The physical limitations associated with health conditions of developmental disabilities place patients at higher risk than the general population of such conditions as heart disease, stroke, and diabetes, at least related to restricted movement, self-care challenges, decreased caregiver assistance, and other impairments. (Stiefel, 2002).

The mouth has been called "the lifeline" for the person who has developmental disabilities. "Severity of medical conditions and perceived general health are significantly correlated with dental functional status and severity of dental disease, and . . . the available data indicate that the impact of dental conditions is pervasive and significant (p. 30-S)," according to Stiefel (2002).

“Neglect of oral hygiene and advanced periodontal disease are the predominant oral health problems of persons with developmental disabilities irrespective of whether they reside in
large institutions, smaller regional facilities, or group homes (p. 31-S).” Stiefel (2002).

Training in SND is available through post-doctoral education as well as in the pre-doctoral coursework for the dental professional. Enhancement of the knowledge, instrumentation and motivation of dentists in their approach to serving members of the population who have developmental disabilities continues to be critical.

Spectrum of Treatment Response

The literature of special needs dentistry indicates a spectrum of response to the challenge of delivering services to individual adult patients who have developmental disabilities. Harvey Levy, D.M.D. (2010) advocates for serving clients with special needs, articulating in his popular article and basis for extensive public speaking 27 different “myths” concerning treatment to members of this population. Levy classifies frequently voiced objections into categories of administrative, management, medical, and financial issues, each item of which he refutes. Levy assumes an aggressive stance, detailing the contrast between good, reliable patients who have special needs and those non-special needs patients who are, in his view, less desirable in practical terms. He cites the rewarding aspects of serving clients with special needs, which he shares, helps him maintain his enthusiasm about dentistry at the same level he had when entering the profession 36 years ago.

Maureen Romer, D.D.S. (2009) provides background in a different avenue of advocacy in “Consent, Restraint, and People with Special Needs,” which offers a review of the literature pertinent to ethical and legal implication and guidelines associated with informed consent and use of restrain regarding patients with special needs. Romer’s examination offers useful philosophical as well as practical clarification associated with an important and difficult area of dental practice, appropriate to a wide range of professionals.

Weil and Inglehart (2010) examined dentists’ behavior and attitudes regarding patients who have Autism Spectrum Disorders (ASD), and found that 89% of pediatric dentists and 32% of general dentists treat patients who have ASD. A positive correlation was reported in the study between use of behavior management strategies when treating patients with ASD and the quality of dentists’ educational experiences. Although dentists disagreed with statements that the pre-doctoral training for treating patients with special needs was adequate, dentists indicated that the better prepared they were, the more likely that they would treat patients with special needs.

Lampert and Tepper (2010) specify the importance of increasing preventive awareness for individuals in the elderly populations, to ensure that “not just oral health, but overall systemic health . . .” is addressed, “thereby improving their quality of life.

Krause, et al. (2010) performed a survey of dental schools in the United States and Canada, to identify ways in which the schools teach future dentists about patients who have special needs. Twenty-two dental schools were represented in an online survey. 91% of programs participating covered the topic as part of clinical education, and 64% provided a special course in treating patients with special needs. 37% had a special area or clinic for treating these patients, and had between 3-22 chairs. Curriculum overload was cited as the greatest challenge (55%) by responding institutions, and 77% of responding schools planned educational changes in the coming three-year period, with 36% planning to increase clinical experiences and 27% working toward “extramural” experiences.

Rapalo, et al. (2010) performed a review of the literature and consulted the 2007 Florida Behavioral Risk Factor Surveillance System (BRFSS), to determine that lack of access to dental care due to cost was higher for individuals with one or more disabilities. Following adjustment for confounding variables, “Floridians with disabilities were 60% more likely to report cost as a barrier to dental care.” p.133. (Rapalo, et al., 2010).

State of Public Funding of Oral Healthcare

The American Dental Association (2010) identified trends in Medicaid coverage of oral healthcare for adults from FY 2002 – 2010. A comprehensive summary by State is included in Appendix G. Categories of funding ranged from full through no coverage for adults. Chart 2 shows summary numbers for the 50 States plus District of Columbia:

Chart 2: Adult (Age 21+) Dental Benefits in Medicaid: FY 2002 – 2010

Level	2002	2003	2004	2005	2006	2007	2008	2009	2010
Full	13	09	08	09	10	11	11	09	09
Limited	13	17	17	15	18	18	19	18	18
Emergency	17	18	19	19	16	15	15	16	14
None	08	07	07	08	07	07	06	08	10

The summary table reveals a recent trend toward decreasing full and emergency coverage, with an increase in states in the number providing no oral healthcare benefits for adults. The American Dental Association defines "limited," based upon a 2000 Government Accounting Office study that defined the term as follows: "States do not cover particular services (preventive, diagnostic, restorative, or more complex), or impose other limitations on coverage, such as a $475 annual ceiling." The term "limited," thus may vary from state-to-state. Minnesota, one of the states with a limited adult benefit, recently, as of July 2011, had legislation introduced that would expand adult coverage to the "aged, blind and disabled," a defined term under the Social Security Act. ADA is currently supporting House Resolution 1606, which would seek to accomplish the same thing at a 100% federal share of cost (See Appendix C).

At the time of the update shown in Chart 2, Arizona had dental services limited to emergencies, medically necessary dentures, and pre-transplant services. At that time, there was a proposal to eliminate all dental care. **Effective October 1, 2010, most dental coverage, including emergency coverage, was discontinued for adults 21 years of age and older.**

Selected Recent Approaches to Addressing the Challenge

Selected approaches to addressing the challenge of delivering SND services are referenced in this section of the report, for purposes of identifying potential considerations for the ADDPC.

The Centers for Disease Control and Prevention (CDC) has recognized "best practices" in systematic oral health surveillance. Among those recognized was North Dakota's Oral Health Surveillance Program (2008). The CDC defines public health surveillance as "the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice," according to the Association of State & Territorial Dental Directors (May 17, 2011). A state-based oral health surveillance system should monitor oral disease status, determine trends, and identify groups that bear the greatest burden of oral diseases.

At the Yeshiva School of Medicine's Einstein Special Care Dentistry Unit, some 5,000 patients, 500 of whom have severe physical or mental impairments, are seen each year. The following information from the School's website (2011) summarizes the benefits of the Children's Evaluation and Research Center (CERC), in operation for more than 50 years:

> *The relative cost savings of the CERC outpatient treatment is significant. "Without the CERC program, these individuals would require general anesthesia in a hospital operating room at a total cost of between $7,000 and $10,000 per procedure, even for a simple cleaning," said Robert Marion, M.D., executive director of CERC and the Ruth L. Gottesman chair in Developmental Pediatrics. 'The CERC dental clinic performs sedation procedures at a cost of approximately $250 each. If the procedures we do for our patients were done in a hospital setting, the cost to the city, state and federal governments could reach $5 million per year versus a modest $125,000 at CERC.'*

Glassman, et al. (2006) described a State of Florida-based initiative involving caregiver training to determine the effects of a training initiative where caregivers were trained and adult clients were studied for effects in community care settings. A multiple baseline design, across three group homes, included 11 adult clients with developmental disabilities. Under study were effects of training, the use of training and coaching on the presence of caregivers during oral hygiene sessions, the duration of teeth-brushing and the 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.

The Office of Oral Health in the Massachusetts Department of Public Health (2010 p.36) indicated the need for widespread access to oral healthcare prevention for senior adults, notably those residing in health care facilities. The necessity of serving members of the adult population who have developmental disabilities share features of need suggested by the study. Specific suggestions included regularly scheduled oral health screenings upon admission to long-term care facilities, inclusion of a dental health professional in the regular care plan for patients, development and implementation of individualized care plans, and routine education in oral healthcare for nursing staff.

Demographics and Eligibility for Services of Arizona Adults with Developmental Disabilities

The population of Arizona's major cities is referenced, using the Gollay & Associates estimate of 1.8%, utilized by the Federal Administration on Developmental Disabilities to extrapolate prevalence rates. Charts 3, 4, summarize city, county, and statewide population statistics.

Chart 3: Arizona Population Statistics by Largest Cities: U.S. Census 2010

City	Population	Change Over 2000	Pop DD (rounded)
Phoenix	1,445,632	9.40%	26,021
Tucson	520,116	6.90%	9,362
Mesa	439,041	10.80%	7,903
Chandler	236,123	33.70%	4,250
Glendale	226,721	3.60%	4,081
Scottsdale	217,385	7.20%	3,913
Gilbert	208,543	90%	3,754
Tempe	161,719	2%	2,911
Peoria	154,065	42.20%	2,773
Surprise	117,517	281%	2,115
Yuma	93,064	20.10%	1,675
Avondale	76,238	112.50%	1,372
Flagstaff	65,870	24.50%	1,186
Goodyear	65,275	245.20%	1,175
Lake Havasu City	52,527	25.20%	945
Buckeye	50,876	678.30%	915
Casa Grande	48,571	92.50%	874
Sierra Vista	43,888	16.20%	790
Maricopa	43,482	4081%	783
Oro Valley	41,011	38.10%	738
Total	4,307,664		77,536

The national prevalence rate for developmental disabilities in the U.S. is 1.8 percent, based on an estimate conducted by Golay & Associates and used by the Federal Administration on Developmental Disabilities to extrapolate state level prevalence rates. As noted below in Chart 4, there is an additional estimated population of 37,522 individuals living in rural areas not accounted for in the estimated population of Arizona's major cities and towns.

Chart 4: Arizona Population by County: 2010 U.S. Census Statistics

County	Population	Change Over 2000	Pop DD (rounded)
Apache	71,518	3%	1,287
Cochise	131,346	11.50%	2,364
Coconino	134,421	15.60%	2,420
Gila	53,597	4.40%	965
Graham	37,220	11.10%	670
Greenlee	8,437	-1.30%	152
La Paz	20,489	3.90%	369
Maricopa	3,817,117	24.20%	68,708
Mohave	200,186	29.10%	3,603
Navajo	107,449	10.20%	1,934
Pima	980,263	16.20%	17,645
Pinal	375,770	109.10%	6,764
Santa Cruz	47,420	23.60%	854
Yavapai	211,033	22.30%	3,799
Yuma	195,751	22.30%	3,524
Total	6,392,017		115,058

Charts 5 and 6 indicate age and ethnic distribution of adults with developmental disabilities in Arizona, based upon point-in-time data from the Arizona Department of Economic Security, Division of Developmental Disabilities, May 31, 2011.

Chart 5: Age Distribution of Adults with Developmental Disabilities in Arizona

Age Range	Number
18 – 21	1,893
21 – 55	9,484
55+	1,490
Total	12,822

Chart 6: Age and Ethnic Distribution of Arizona Adults with Developmental Disabilities

Age Range	Asian	African American	Caucasian	Hispanic	Native American	Unknown	No Ethnicity Code	Totals
18-21	23	131	1,018	557	95	49	20	1,893
21-55	132	542	5,810	2,111	704	132	53	9,484
55+	11	63	1,016	255	84	7	9	1,490
Totals	166	736	7,844	2923	883	188	82	12,822

Chart 7 identifies a point-in-time summary of documented disabilities served by ADES, DDD by all age groups in Arizona, as of May 31, 2011.

Chart 7: Documented Disabilities in Arizona's Population Served by ADES/DDD

Documented Disability	Number	Percentage
Autistic	4,514	14%
Cerebral Palsy	2,957	9%
Cognitive Disability	13,739	44%
Epilepsy	1,243	4%
At Risk (0-6 Evaluation)	8,764	28%
Not Indicated	103	0%
Total	31,320	100%

Source: Arizona Department of Economic Security Division of Developmental Disabilities
Point in Time May 31, 2011

Shaffer (2011) summarizes the federal definition of developmental disabilities in the Developmental Disabilities Act, section 102(8), "the term 'developmental disability' means:

> a severe, chronic disability of an individual 5 years of age or older that:
>
> 1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
> 2. Is manifested before the individual attains age 22;
> 3. Is likely to continue indefinitely;
> 4. Results in substantial functional limitations in three or more of the following areas of major life activity; (i) Self-care; (ii) Receptive and expressive language; (iii) Learning; (iv) Mobility; (v) Self-direction; (vi) Capacity for independent living; and (vii) Economic self-sufficiency.

Arizona Statutes (2011) define developmental disabilities in conformance with but more specifically than the federal definition, noting four qualifying conditions: "Is attributable to cognitive disability, cerebral palsy, epilepsy or autism." Further specific information includes:

> (b) Is manifested before age eighteen.
>
> (c) Is likely to continue indefinitely.
>
> (d) Results in substantial functional limitations in three or more of the following areas of major life activity: (i) Self-care. (ii) Receptive and expressive language. (iii) Learning. (iv) Mobility. (v) Self-direction. (vi) Capacity for independent living. (vii) Economic self-sufficiency, and (e) Reflects the need for a combination and sequence of individually planned or coordinated special, interdisciplinary or generic care, treatment or other services that are of lifelong or extended duration.

Chart 8 summarizes adults age 21 or older participation in insurance plans, inclusive of specific plan and multiple enrollments.

Adult Member Count with Private Medical Insurance, Medicare, or Both

Chart 8: Age 21 or Older Member Insurance Count Having Private, Medicare, or Both

Health Plan	Private	Medicare	Both	Total With	% of Pop	Pop w/o Private Coverage	Total Population
Arizona Physicians IPA	543	1,615	626	2784	64.28%	1,547	4,331
Capstone	97	431	98	626	66.31%	318	944
Care 1st Healthplan of AZ	24	64	23	111	62.71%	66	177
Indian Health Services	15	88	29	132	44.15%	167	299
Mercy Care Plan	418	1,388	452	2,528	65.53%	1,188	3446
Total	1,097	3,586	1,228	6,181		3,286	9,197

Chart 9 indicates those individuals with developmental disabilities (all age groups) served by health plans according to Arizona counties.

Chart 9: Individuals Served by Health Plan by Arizona County

Counts by Health Plan and County						
County	Care 1st	APIPA	CAP	MCP	OTHER	Total
Not Defined	4	82	6	38	2	132
Apache	0	23	72	0	170	265
Cochise	0	279	0	95	0	374
Coconino	0	54	407	0	79	540
Gila	0	16	0	163	22	201
Graham	0	9	0	99	5	113
Greenlee	0	2	0	28	0	30
La Paz	0	30	0	1	11	42
Maricopa	745	7,322	0	6,345	92	14,504
Mohave	0	97	406	0	4	507
Navajo	0	43	186	0	123	352
Pima	0	2,740	0	989	34	3,763
Pinal	0	321	0	845	36	1,202
Santa Cruz	0	113	0	37	0	150
Yavapai	0	137	660	0	4	801
Yuma	0	395	0	127	1	523
Total	749	11,663	1,737	8,767	583	23,499

Summary of Interview and Focus Group Input from Dental Professionals

For purposes of conducting the study, 19 dental professionals participated in two separate focus groups, in addition to 15 individual dentists and 5 dental hygienists who participated in face-to-face and telephone interviews, representing a total of 34 dentists and 5 dental hygienists. Interviews and focus groups were conducted between January 30 and June 24, 2011. Dentists were selected from the following sources:

- Arizona Dental Foundation roster of dentists who have participated in or are currently enrolled in SND training
- Arizona Reduced Fee and Community Dental Clinics list of dentists who serve the population of adults with developmental disabilities.

Interview and focus group protocols were developed in advance of scheduling and conducting meetings with dental professionals. Protocols were distributed to multiple agencies for input. The finalized versions of interview and focus group questions appear in Appendix B.

Four broad areas of content were addressed in each of the focus groups and individual interviews, and the content collected was analyzed and synthesized by category. For purposes of deriving the most valuable information from these meetings, a single summary is provided in this section of the report.

a. Participation in training to treat patients with special needs (When? Where? Length of program? Agency sponsor? Most valuable learning? Additional areas of coverage recommended? Worthy of dentists' time? Extent of application of principles and practices?)
b. Special needs dentistry current practice (Number of patients with special needs seen monthly? Challenges and issues regarding service to adults with developmental disabilities? Special equipment needed? In-office practices or procedures to facilitate service to patients with special needs? Obstacles to serving patients with special needs since training?)
c. Dental care and patient health: system-level (Baseline measures and ongoing maintenance of care? Role of prevention? Care protocols? Risks and their mitigation? Role of caregivers? Integration of dental visits on routine basis into Individual Service Plan (ISP) for consumers receiving services from ADES/DDD?)
d. Innovation and system-level service provision (Role of tele-dentistry? Role of mobile dentistry? Roles of non-profit and for-profit provider organizations in service of patients with special needs? Billing and funding? Insurance concerns? Public and private funding mechanisms? Reduced and free service provision to patients with special needs?)

1. Participation in SND Training and Education

Of the 34 dentists who took part in focus groups and individual interviews, 23 had participated in clinics and training for SND as continuing education credit, while two reported exposure to SND as part of university, pre-service education. The remaining dentists indicated that they had experienced exposure to the field of SND through their own educational methods and practice.

Dentists indicated that they believed training in SND to be important, beneficial, and helpful, notably when hands-on, clinical exercises are present, to clarify and fortify the practical application of methods in a real-world setting. Some dentists interviewed suggested that classroom-style learning was interesting, but less effective than an integrated classroom and practice-based model.

Dentists uniformly indicated the following responses to questions regarding "most valuable learning" during their SND programs:

- Not to fear patients with developmental disabilities
- Ways of communicating with patients who have special needs
- How to prop open the mouth of patients who do not have the muscular ability to hold their mouths open
- Level of medication required to ensure safe and proper treatment of dental patients

One of the focus group discussions referenced the work of popular speaker and author, Harvey Levy, D.M.D. (2010) who wrote "Debunking the Myths about Special Needs Patient Care." This article cites 27 different claims that are frequently used by dental professionals as reasons to refrain from serving the population of adult consumers who have developmental disabilities. Levy challenges each of these presumed barriers in four categories: administrative, managerial, medical, and financial. Levy's recent presentation in March of 2011 in Arizona, was deemed persuasive in arguing for serving adults with developmental disabilities, in addition to other individuals with challenges.

SND should become an established category of practice, according to several dentists interviewed for this study. Historically, SND was relegated to the province of pediatric dentists. Dentists interviewed stated that this approach is changing, with an increasing number of general practice dentists gaining continuing education in the interest of being prepared to serve patients who have developmental disabilities.

2. SND Current Practice

The majority of dentists interviewed for this study, despite having received training in SND, only infrequently treat patients with developmental disabilities. Among the responses most frequently received were:

- "Not a lot" (2-3 per month)
- "2 per year"
- "Probably 1-2 per year"

Two different dentists of the total interviewed gave the following responses:

- "30-50 per month"
- "Our office is the end of the line. We offer comprehensive service with full anesthesia to 100% of patients who are referred by other practitioners. All of our patients require special care."

The majority of dentists interviewed did not actively seek to build their caseload of patients with developmental disabilities. Rather, in instances where these patients contacted the dental offices, dentists stated that they felt more comfortable accepting and treating these patients than they would have without the training.

Based upon the training received during SND training dentists were aware of multiple support items that can be useful for treating patients, including:

- Cocoon wrap around body
- Industrial strength mouth props
- Special wrap to keep limbs from flailing

While aware of the availability of such items, the majority of dentists had not purchased these for their practice, based, in part, upon the low volume of patients with special needs served.

Establishing proper transportation schedule, preferably including the caregiver, rather than solely the driver of the van, is preferable to dentists, who also advocated scheduling patients at a time in the day when their wait time can be minimized, and services can be delivered upon patients' arrival.

Dentists also referred to various hospitals with the capability to deliver intravenous general anesthesia, with a built-in operating room, including high-speed fiber optic capability. Among those hospitals noted were the Phoenix-based Paradise Valley Hospital and Good Samaritan Hospital.

Dentists further specified several external obstacles pertaining to the care of adult patients with developmental disabilities.

Court-Appointed Fiduciary One issue voiced by dentists in a focus group involved the court-appointed fiduciary role. According to dentists, this role exists to serve patients unable to handle their fiduciary responsibilities directly, and who do not have another family member or associate who is available to function in their stead. In these cases, the court appoints an available fiduciary. Dentists suggested that fiduciaries responsible for adult individuals with developmental disabilities may not consistently ensure that oral healthcare is provided to these consumers. According to dentists participating in the study, some necessary dental procedures have been denied the patient, against the advice of the dentist.

Transportation and Regular Scheduling of Consumers Ensuring that agencies and caregivers maintain regular dental visits for adults with developmental disabilities remains a difficulty, as both scheduling and transportation remain acknowledged issues.

Trend Toward Reduction in Fees to Dentists by Insurance Plan Providers According to dentists, consistent and gradual decreases in fees provided to dentists by such providers as Mercy Care has been demonstrated over recent years. In effect, said dentists, there is a de facto disincentive to treat patients with special needs, based upon an increased amount of time and manpower required to serve certain patients (four different dentists referred to a need for three people to assist the dentist when treating selected patients with special needs), and a lower reimbursement for services delivered.

The Cost of Anesthesia is Generally High Where it is Required Dentists appear to present two views, representing the ends of the spectrum regarding this issue. Those dentists who advocate for the care of patients with developmental disabilities argue against presumed challenges voiced by their peers in the field, minimizing the issues pertaining to anesthesia. At the other end of the discourse, other dentists express concern over the financial requirements and special training needed to provide extensive anesthesia to patients who have special needs.

3. Dental care and patient health: system-level

Dentists indicated that establishing baseline measures for care, and ensuring ongoing maintenance of teeth and gums was highly dependent upon prevention, care protocols, and risk mitigation. The role of caregivers, the routine scheduling of dental visits, and the integration of oral healthcare measures into the Individual Service Plan (ISP) of adults with developmental disabilities remain critical to ensuring patients' health.

Among the most salient challenges to achieving these goals, according to participating dentists, were the following:

Need to Systematize Training and Prevention Services for Caregivers in Group Homes Dentists indicated that systematic training of caregivers in prevention services to clients in an effort to strengthen, support and mitigate limitations based upon physical, intellectual, emotional, or medicinal issues. According to participating dentists, regular preventive care is essential to the oral care and general health of patients. A regimen of brushing, flossing, and the elimination of soda pop, including sugar-based and sugar-free beverages, is vital to oral health, said dentists interviewed.

Difficulties in Third-Party Coding for Special Needs Dentistry Services There was a difference in experience and understanding on the part of different participating dentists regarding the issue of third-party coding practices for billing purposes with private insurance providers. Those dentists participating in the focus group, who indicated that they frequently utilized anesthesia in their practice, voiced the view that "With 'compelling medical need,' and specifying reason for referral, Medicare will cover the cost for patient treatment involving adults with developmental disabilities."

The majority of dentists in general practice expressed the view that they were unable to code staff provider services in such a way as to retrieve proper reimbursement that took into account the actual amount of time and resultant expense that was needed to deliver most services required for SND.

Alternatives to Services Delivered at Free or Reduced Charges Dentists interviewed individually and in focus groups clarified that they frequently provide free or reduced services for adults with developmental disabilities. When asked about alternative opportunities, including potential contributions by private citizens or foundations, dentists participating in interviews indicated that as dental professionals, they are routinely asked for donated services more frequently than they are able to perform such services. Dentists responded favorably to a question regarding their interest in supporting donation programs that extended beyond dental professionals. Such programs would involve foundation, individual, and other funding sources that would support dental professional fees when serving individuals having special needs. ***One dentist stated that he was very tired of being asked to contribute, and that it happened very frequently.***

4. Innovation and system-level service provision

Among dentists interviewed, the majority indicated that comprehensive, direct, and appropriate care customized to the unique needs of each patient must always have the greatest emphasis. As a group, the dentists who participated in this study viewed such service innovations as tele-dentistry, mobile dentistry, and Advanced Dental Hygiene Practitioners (ADHP, or Mid-Level Providers) as potentially useful to the extent that such components were the only available services to selected, remotely located populations.

Dentists discussed various recent innovations in dental service provision:

Tele-Dentistry When asked about the role of tele-dentistry, dentists indicated that the most critical feature of this practice is the quality of the dental care itself. The method is not a panacea, said the dentists interviewed, but it certainly offers a rapid means of providing diagnostic information while reducing travel time for families. Through tele-dentistry, the dental hygienist, using mobile equipment, submits x-rays to the officiating dentist, who performs a comprehensive diagnosis. The family's visit to the dental office involves the dental procedures for which a preliminary diagnosis has been made by a dentist reading x-rays captured and transmitted from a sometimes distant site. Dentists interviewed cautioned that tele-dentistry "is only as good as the practitioner providing services."

Mobile Dentistry The provision of mobile dentistry tends to involve basic cleaning and simple diagnostic services, offered at central locations in a community. Dentists interviewed overwhelmingly expressed a preference for treating patients in dentists' own offices, over going "on location" in a vehicle equipped only partially for treatment. Dentists preferred to deliver services with their own equipment and materials readily available. Dentists placed strong value on their ability to offer the patient all of the advantages of full preparation and capabilities, thereby allowing and facilitating complete dental care.

Advanced Dental Hygiene Practitioner (ADHP, or Mid-Level Provider) Issues pertaining to professional accountability and liability were identified by dentists in relation to the concept of the ADHP. While potentially valuable, this professional typically linked to a dentist, who is professionally responsible for all procedures and treatment of patients seen by the ADHP.

Potential for Waste of Funds In addition, dentists participating in focus groups were asked about the use of tele-dentistry and mobile dentistry, with the principle of outreach in mind. Several participants remarked that both of these approaches, while valuable, can have a negative effect on the system-level provision of care. Specifically, the argument can be summarized as follows, based upon views shared by dentists participating:

> *Adult patients who have developmental disabilities must be served both by prevention and treatment. Both tele-dentistry and mobile dentistry are designed to provide preliminary services, inclusive of cleaning and examinations. With limited or no funding for dental needs, such preliminary services, provided without the full complement of dental equipment (in the dentists' own offices), and provided for large numbers of patients, such approaches can drain the scant funding without providing the full care that is needed by many individual consumers who very likely will have needs that extend far beyond brief, basic service provision. With limited resources, such services may, in fact, 'take the benefits out of the system' and make money for limited sectors of the care system, without serving the primary and extensive, real-life needs of patients.*

Non-Profit Versus For-Profit Service Delivery A further issue of non-profit status for organizations versus private dental practice, is that the non-profit status, in fact, provides for more lucrative ways of growing a non-profit organization, which also qualifies for grant funding. No private professional practice is eligible for such funding. Dentists interviewed indicated that the for-profit dental practices must be supported, to provide effective oral healthcare services. These practitioners advised that the provision of basic cleaning services in a convenient way, can conflict with full-service dentistry. Simple screening may represent only a fraction of the needed services. If limited available funding is expended on simple services, clients' needs may not be served effectively.

Noteworthy Efforts Occurring in Other States When asked about noteworthy endeavors occurring in other states, dental professionals made reference to activities at the University of Alabama, where a concerted effort to integrate SND training into the curriculum of the Dental School. In addition, a complement of continuing education courses in special needs is provided by the University.

Summary of Interview and Focus Group Input from Stakeholder Professionals

For purposes of conducting the study, 30 individual interviews and two focus groups were conducted with stakeholder professionals who have a vested interest in the healthcare of adult individuals with developmental disabilities who reside in Arizona. Interviews and focus groups were conducted between January 30 and May 24, 2011. Participants in interviews included representatives of the following organizational and functional areas:

- State government
- Local government
- Nonprofits
- Caregiver supervisors
- Healthcare providers
- Parents and families of Adults with developmental disabilities

Interview and focus group protocols were developed in advance of scheduling and conducting meetings with stakeholders. Protocols were distributed to multiple agencies for input, and detailed recommendations for changes were explored with the Executive Director of ADDPC. The finalized versions of interview and focus group questions appear in Appendix B.

Four broad areas of content were addressed in each of interviews, and the content collected was analyzed and synthesized by category. For purposes of deriving the most valuable information from these meetings, a single summary is provided in this section of the report.

1. Preventive Measures Required for Serving Adults with Developmental Disabilities (What preventive measures are considered optimal? Who needs to perform these?)
2. Education and Training Needs for Serving Population (Types of training? Training context? Focal points of training? Target audience for training?)
3. Systems for Supporting Oral Healthcare (Structured approach? Specific components? Supporting partners? Role of caregivers? Integration of dental visits on routine basis into Individual Program Plan (IPP) for consumers? Family and consumer supports?)
4. Top Priorities for Oral Healthcare (High-impact actions? Roles of partnering institutions? Areas of opportunity? Points of focus? Resolution of issues and concerns?).

1. Preventive Measures Required for Serving Adults with Developmental Disabilities.

Healthcare professionals and other stakeholders emphasized the importance of taking the following actions to ensure the oral health of adult consumers:

- Assume a proactive stance toward brushing and flossing on the part of caregivers; do not merely give the client a toothbrush and ask him or her to brush.
- Provide the appropriate assistive technology for frequent preventive care for teeth, and deliver routine assistance.
- Plan for and support a healthy diet, emphasizing the absence of sweetened foods, and the elimination of sweetened, sugary soda drinks.
- Establish a regimen of regular visits to a dental hygienist for cleaning and screening, preferably twice or more yearly, to ensure up-to-date status reports.
- Educate caregivers in the recognition of signals associated with pain and discomfort associated with oral health problems.

Healthcare professionals responsible for growing the availability of funds for the care of adults with developmental disabilities should actively recruit dental professionals to serve special needs populations. According to one health care professional, the ideal provider of dental services to adult consumers possesses these traits:

- Charismatic and welcoming to patients
- Passionate about serving special needs populations
- Professional in delivering services
- Committed to making appropriate accommodations that serve clients having special needs

2. Education and Training Needs for Serving Population

According to interviewees, two areas pertaining to education and training need to be acknowledged:

- Education about the context of oral healthcare in general health and well-being of adult consumers, and
- Training in specific measures to invest in prevention of serious health challenges that derive from neglect of oral care.

According to stakeholders interviewed, the education of caregivers to adults with developmental disabilities does not address the direct relationship between oral healthcare and general patient health. Not only are direct caregivers given no information about the risks of not including oral healthcare, employees serving the residential, support, and training needs of adult consumers are likely to possess little to no awareness of the seriousness of neglecting dental health. Among the risks cited by healthcare professionals in the general group of stakeholders interviewed were:

- Infections due to abscessed teeth
- Inability to eat, based upon dental infection
- Weight loss as a function of the inability to eat meals
- Gingivitis
- Infected gums
- Aspiration pneumonia
- Cardiac challenges

The prevalence of challenges associated with preventive care for adults with developmental disabilities is likely to be greater than they are for the general population of adults, based upon the difficulty of providing personal care for teeth. A combination of factors can contribute to reported neglect:

- Difficulty in accessing clients' teeth, based upon motor-based difficulties
- The inability of many adult consumers to convey specific information about their conditions, resulting in inevitable delay in obtaining care to address immediate concerns
- Possible disinclination on the part of caregivers, based upon likely resistance by the adult consumers themselves
- Risk of physical harm or infection, such as being bitten, due to involuntary physical responses of consumers
- The numerous responsibilities that are included in the caregiver job description, resulting in the perception that oral healthcare prevention constitutes just "one more thing" that is expected of caregivers

The practices to be advocated for in the training of caregivers constitute fairly simple elements:

- Brush teeth. Ensure complete and careful brushing of teeth on a routine basis. If client cannot perform the task, provide assistance or perform the task for the client.
- Floss teeth. Include daily or more frequent flossing of teeth, to remove food particles from areas between teeth. If client cannot perform task, provide assistance or perform the task for the client.
- Dental visits. Schedule and carry out dental visits for cleaning and checkups no less frequently than twice per year.

3. **Systems for Supporting Oral Healthcare.** (Structured approach? Specific components? Supporting partners? Role of caregivers? Integration of dental visits on routine basis into Individual Program Plan (IPP) for consumers?)

    - Include Oral Healthcare Prevention in Individual Program Plan (IPP). Stakeholders representing nonprofit caregiver organizations have indicated that oral healthcare is "honestly a lower priority" than other elements included on the Individual Program Plan. There is not a specific protocol that is incorporated into the IPP, resulting in a non-graded area that is relegated to inattention on the part of the agency providing care. Respondents indicated that this situation reflects the lack of knowledge on the part of the general public relative to the integral importance of oral healthcare as the "gateway to physical health" of every person, according to a healthcare professional who was interviewed for this study.

    A family participant in the individual interview suggested that there is no place on the IPP for dental preventive care. "No place on the form" that she is aware of, as an active parent guardian, provides space for indicating Oral Health procedures and practices.

    - Replace Emergency Room Visits with Prevention. Both a nurse practitioner with experience in Emergency Room (ER) care and several dentists interviewed for this study conveyed that a frequent reason for visits to the ER by adults having developmental disabilities is dentally-related. Among the chief oral health problems are these:

        - abscessed teeth
        - broken teeth
        - impacted teeth
        - broken crowns

    Given that no dental professionals are assigned to ER duty, other medical doctors are responsible for treating individual patients who come to the ER to the best of their ability. The most frequent responses to the above-referenced dental concerns are the following:

        - Referral to a dental professional
        - Pain medication (lance injection of Novocain) or Vicodin
        - Antibiotic, in case of infection

In the case of referral to a dentist, many patients do not or cannot seek subsequent assistance from a dental office. Where pain medication and/or antibiotics are administered, temporary relief is offered, without treating the cause of the pain and discomfort.

Gain and observe specific information about ER procedures One interviewee reported that a particular ER maintained a "dental toolbox" on premises, to be used by medical doctors in cases where minor surgical procedures were required to relieve suffering of patients.

Remain vigilant about diagnoses and prescribed recommendations in emergency room Another interviewee indicated that her son had been taken to the emergency room a few days following a visit to the primary care physician, who diagnosed aspiration pneumonia. The consumer had only days before been to the dentist for a routine (six-month) visit for teeth cleaning. Very large amounts of displaced plaque had been in the consumer's mouth following the cleaning, in addition to the water in his mouth and the dental drill in the context of his inability to swallow, due to a birth defect, resulted in panic, and the particles that aspirated caused further difficulty. The parent instituted a system of monthly visits to the dentist for cleaning, paid for by the consumer, to reduce the amount of displaced plaque. While costly, the mother has asserted that frequent, regular oral care has improved the consumer's quality of life. Her son has been able to pursue activities in his day program, participate in activities in the group home where he lives, and generally be a full participant in his life. His IPP reports have indicated improved ability to function, including his ability to participate in occupational therapy-related activities.

4. Top Priorities for Oral Healthcare

Educate the public about the direct relationship of oral health and overall well-being. The majority of respondents articulated "public education" as a critically important feature to be emphasized regarding oral healthcare, notably that of adult consumers with developmental disabilities, for purposes of this study. **According to healthcare professionals interviewed, the general public does not associate oral healthcare with the general medical health of individuals.** This is a false perception that can result in life-threatening situations. Adults with developmental disabilities represent a vulnerable population that may require any or all of the following to perform routine, preventive care:

- Proper diet and nutrition, specifically the elimination of sugary beverages and sweets, which are detrimental to oral healthcare
- One-on-one assistance by a trained caregiver
- Assistive technology, such as a flosser and/or a mechanical toothbrush

Create a database of needs. Stakeholder interviews representing a wide spectrum of knowledge pertinent to the issue of oral healthcare indicated the efficacy of large-scale solutions, rather than identifying individually-focused solutions. While all cases were acknowledged by interviewees to reflect larger-scale concerns, the presence of needs shared in common by adult consumers warrants data gathering, classification, notification, and referral to the appropriate professional.

One family cited a person with developmental disabilities who had two abscessed teeth that constituted a medical emergency. The family paid out-of-pocket.

Another interviewee related a success story pertaining to donated services on the part of a dentist who was advised by a nurse of a significant health risk by an adult consumer. The dentist provided a top denture and bottom implants for the patient, completely free of charge. According to the stakeholder interviewed for this study, the work would have cost approximately $10,000.

At present, multiple issues of oral healthcare need exist in isolation, with insufficient knowledge of or access to the needed oral healthcare provider. Similarly, according to stakeholders, the majority of dentists may accept the occasional adult with developmental disabilities. However, there appears not to be a proactive effort on the part of dentists to seek patients with developmental disabilities.

Fund preventive care. According to stakeholders, adults who do not have insurance or funds to pay for dental care, are simply not going to the dentist. "They are going without," was the response to the question of how consumers are addressing their oral healthcare needs. "The absence of funding has become a recipe for neglect," said one stakeholder. "Not only is regular, preventive dental care left out of the healthcare equation, treatment for existing dental problems is also absent."

"Among the serious health consequences of neglect of oral healthcare for a period of two to three years can result in diabetes and/or heart disease," according to professionals in the health care community who participated in the interviews. These clients, many of whom have "no voice for themselves," are being placed in a compromising position relative to their health and well-being.

Interviewees voiced concern over the system's inherently funding very late symptoms, rather than causes. One interviewee put it succinctly, saying: "Extraction due to an emergency is funded; routine care is not," under AHCCCS.

Funding, at a minimum, one dental visit per year for prevention purposes would make a strong and vital contribution to the care of adult consumers, according to numerous interviewees in the provider group.

A rampant pattern of "undertreatment" prevails, said stakeholder participants in the study. Patients will pay a high price in illness and emergency treatment, often without addressing the root cause of pain, discomfort, and dangerous health conditions.

Approximately half of the stakeholders interviewed were familiar with tele-dentistry, and expressed interest in its potential to improve efficiency of oral healthcare, notably for purposes of reducing the number of trips made to dental practitioners from residents of rural Arizona.

Fund emergency care. Of primary importance is the funding of emergency dental care. Interviewees relayed that once dental pain has grown to the extent of taking consumers to the ER, it is already "too late" to address the problem without undue time and effort, thereby further challenging the well-being of the patient. Unnecessary delays brought about by the failure to gain treatment for initially simple concerns may result in serious health consequences that extend far beyond those associated with oral health.

Donation of services: optimal approaches Interviewees have noted the potential for alternative approaches to oral healthcare, based upon the current absence of funding and scarcity of dental practitioners in remote locations. Participants in one-on-one interviews have noted that the gaps in care are substantial. Current practices can be described as follows:

Where "serious" situations exist, families who are able to pay, do so "out of pocket" to alleviate extreme suffering of their family member. Invariably, care is provided too late to be optimally helpful to the patient. Neglect of oral healthcare leads to other serious illness.

Solicit champions for support One interviewee enthusiastically stated that recruitment of charismatic, passionate, professional providers of care would be a major step in voicing the dramatic issue of the importance of oral healthcare for adults with developmental disabilities. At present, scattered "voices" can be heard expressing concerns regarding an individual patient. No single voice represents the numerous adult consumers having developmental disabilities.

The cadre of champions proposed would need leverage, methods, and access to a wide range of potentially helpful providers.

Costs of Dental Services in Arizona by County

Cost Information by Arizona County

Purposes

Data regarding the cost of dental services in the State of Arizona were gathered for the following purposes:

1. To identify standard costs for selected dental services in Arizona counties.
2. To explore the potential for optimizing oral health of adults with developmental disabilities.
3. To establish comparisons between the cost of preventive care versus treatment.
4. To identify approaches to oral healthcare projected to invest in prevention services while seeking to prevent the necessity for selected high-cost services.
5. To establish a system for adults with developmental disabilities in Arizona that involved an initial diagnosis and selection of plan to support oral healthcare needs.

Method

In an effort to obtain ranges of costs for a sample of frequently needed dental procedures, the research team utilized the Arizona Dental Association list of dental offices and the Qwest telephone directory, where necessary. The determination of securing self-pay information was made, based upon the prevalence of this circumstance regarding the majority of dental services to adults. Specific cost information for self-pay regarding the following dental services was provided: (1) New patient examinations, x-rays, and cleanings; (2) Cavity fillings; (3) Root canal; (4) Crown; (5) Tooth extraction; (6) Dental implants; and (7) Dentures. The researcher obtained sample information from all counties, with the exception of the following: Pinal County and Santa Cruz County. Graham and Greenlee Counties are reported as a combined service area, for purposes of this report, based upon the information received.

Summary

Tables 10 - 22 specify costs of common dental services by range of pricing by Arizona county. Costs are presented by range, from lowest cost, “minimum,” to highest cost, “maximum,” as provided by a sample of dental providers within each county. An examination of the quoted prices for services demonstrates variation within a given type of service, as well as variation among counties in the level of expenditure required for dental work. Of primary importance for this study is the opportunity to utilize these costs for the following purposes:

1. To review cost levels for such relatively low-cost services as tooth extraction, cavity fillings, and dentures, versus relatively higher costs such as root canals and crowns.
2. To perform calculations for purposes of supporting or refuting qualitative input provided in this study by consumer respondents to the survey.
3. To propose and examine several scenarios, based upon specific health conditions and age categories of current adult consumers, for the purpose of designing plans that support the health and financial well-being of consumers and citizens.

Chart 10: Apache County Dental Services

Apache County: Sample Size of 3 of 3 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 160.00	$ 185.00
Cavity Fillings	$ 130.00	$ 255.00
Root Canal	$ 540.00	$ 765.00
Crown	$ 725.00	$ 855.00
Tooth Extraction	$ 99.00	$ 239.00
Dental Implants	Specialist	Specialist
Dentures	Specialist	Specialist

“People don’t realize that dental infection can lead to death.”

Chart 11: Cochise County Dental Services

Cochise County: Sample Size of 5 of 27 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 163.00	$ 250.00
Cavity Fillings	$ 109.00	$ 322.00
Root Canal	$ 520.00	$ 780.00
Crown	$ 795.00	$ 1,300.00
Tooth Extraction	$ 110.00	$ 180.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 1,205.00	$ 2,000.00

Chart 12: Coconino County Dental Services

Coconino County: Sample Size of 9 of 71 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 220.00	$ 300.00
Cavity Fillings	$ 125.00	$ 300.00
Root Canal	$ 650.00	$ 1,100.00
Crown	$ 950.00	$ 1,150.00
Tooth Extraction	$ 140.00	$ 250.00
Dental Implants	$ 1,100.00	$ 2,400.00
Dentures (per denture)	$ 1,350.00	$ 1,700.00

Chart 13: Gila County Dental Services

Gila County: Sample Size of 4 of 11 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 235.00	$ 260.00
Cavity Fillings	$ 129.00	$ 235.00
Root Canal	$ 775.00	$ 900.00
Crown	$ 800.00	$ 950.00
Tooth Extraction	$ 125.00	$ 210.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 1,200.00	$ 1,450.00

Chart 14: Graham/Greenlee County Dental Services

Graham/Greenlee Counties: Sample Size of 4 of 11 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 160.00	$ 220.00
Cavity Fillings	$ 145.00	$ 300.00
Root Canal	$ 650.00	$ 900.00
Crown	$ 700.00	$ 925.00
Tooth Extraction	$ 100.00	$ 210.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	Specialist	Specialist

Chart 15: La Paz County Dental Services

La Paz County: Sample Size of 2 of 3 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 160.00	$ 200.00
Cavity Fillings	$ 110.00	$ 200.00
Root Canal	$ 650.00	$ 800.00
Crown	$ 800.00	$ 925.00
Tooth Extraction	$ 125.00	$ 200.00
Dental Implants	No Quote	No Quote
Dentures (per denture)	$ 950.00	$ 1,100.00

Chart 16: Maricopa County Dental Services

Maricopa County: Sample Size of 7 of 937 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 140.00	$ 210.00
Cavity Fillings	$ 125.00	$ 330.00
Root Canal	$ 600.00	$ 950.00
Crown	$ 850.00	$ 1,200.00
Tooth Extraction	$ 125.00	$ 300.00
Dental Implants	$ 1,450.00	$ 2,100.00
Dentures (per denture)	$ 1,400.00	$ 1,900.00

Chart 17: Mohave County Dental Services

Mohave County: Sample Size of 5 of 52 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 240.00	$ 290.00
Cavity Fillings	$ 100.00	$ 225.00
Root Canal	$ 500.00	$ 1,000.00
Crown	$ 700.00	$ 1,200.00
Tooth Extraction	$ 100.00	$ 229.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 1,300.00	$ 1,900.00

Chart 18: Navajo County Dental Services

Navajo County: Sample Size of 5 of 20 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 199.00	$ 230.00
Cavity Fillings	$ 100.00	$ 350.00
Root Canal	$ 500.00	$ 800.00
Crown	$ 775.00	$ 1,000.00
Tooth Extraction	$ 100.00	$ 200.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 900.00	$ 1,300.00

Chart 19: Pima County Dental Services

Pima County: Sample Size of 5 of 240 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 140.00	$ 250.00
Cavity Fillings	$ 122.00	$ 320.00
Root Canal	$ 600.00	$ 950.00
Crown	$ 850.00	$ 1,200.00
Tooth Extraction	$ 125.00	$ 290.00
Dental Implants	$ 1,400.00	$ 2,050.00
Dentures (per denture)	$ 1,300.00	$ 1,850.00

Chart 20: Yavapai County Dental Services

Yavapai County: Sample Size of 6 of 58 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 240.00	$ 260.00
Cavity Fillings	$ 85.00	$ 300.00
Root Canal	$ 450.00	$ 900.00
Crown	$ 700.00	$ 1,100.00
Tooth Extraction	$ 95.00	$ 300.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 1,300.00	$ 1,600.00

Chart 21: Yuma County Dental Services

Yuma County: Sample Size of 6 of 30 Providers		
Dental Service	**Low**	**High**
New Patient Exam/X-ray/Cleaning	$ 205.00	$ 300.00
Cavity Fillings	$ 122.00	$ 319.00
Root Canal	$ 750.00	$ 900.00
Crown	$ 750.00	$ 1,100.00
Tooth Extraction	$ 110.00	$ 250.00
Dental Implants	Specialist	Specialist
Dentures (per denture)	$ 1,100.00	$ 3,000.00

Utilization of Cost Estimates for Comparative Approaches

Given the absence of coverage for oral healthcare by the Arizona Health Care Cost Containment System (AHCCCS), some consumers are not visiting the dentist for regular checkups and cleaning. Using cost ranges for preventive services, notably New Patient Exam/X-ray/Cleaning by county, and comparing the costs of more extensive procedures reveals several outcomes:

Utilization of Cost Information for Planning and Strategic Approach

- Dental professionals have recommended preventive care practices, emphasizing home care and professional cleaning and examinations.
- A review of the literature indicates support for prevention efforts; several current and recent studies identify approaches that warrant consideration in Arizona.
- Stakeholders, including health professionals and caregiver organizations, have voiced the practical challenges associated with access to care, implementation of recommended procedures for prevention, and financial issues.
- Consumers and their families have expressed concern about the lack of needed financial support for relatively low-cost prevention activities, and the extremely high costs of more advanced procedures that must be performed due to damage to the teeth, gums, and general health due to prescription medication, as well as long periods of neglect.

Cost information can be used to examine consequences of existing and alternative approaches to addressing the oral healthcare needs of adults in Arizona with developmental disabilities. Several observations can be made, based upon the costs obtained from a sample of dental providers representing counties in Arizona:

1. Investment in Initial Visit. Based upon recommendations from dental professionals and throughout the literature, the investment in having a new patient appointment, gaining baseline information, and having teeth cleaned, is beneficial. It is useful to note that from a financial standpoint, a new patient examination differs in cost from extraction of a single tooth by $0.00 (La Paz County) to $90.00 (Maricopa County).
2. Short-term avoidance of cost outlays for preliminary appointments and appointments for regular cleaning services can easily result in substantially higher costs. For example, crowns range in cost from $855 (Apache County) to $1,300 (Cochise County). When root canals are also involved, the cost can become quite high. Precluding such costs is advisable from a health and a financial point of view.
3. Planning for initial appointments and regularly scheduled screening and cleaning, in addition to establishing preventive care implementation in residential facilities, home-based or institutionally-based, optimizes the investment in oral healthcare.

The State of Arizona can benefit from considering the development of a plan that would encompass the following specific elements:

- Establish a cadre of state-appointment dentists authorized to perform and document electronically an initial examination, x-ray, cleaning, and an **individual oral health care plan** for each consumer who has developmental disabilities. Such appointments should be conducted as close to the consumer's home as possible.
- Implement the **individual preventive oral healthcare plan,** and fortify it through the provision of requisite assistive technology to ensure self-care and/or care from an assigned professional caregiver.
- Incorporate an electronic documentation of the results of the initial oral care examination, and **individual preventive oral healthcare plan** into a statewide database.
- Authorize at a state and/or county level the designated, appropriate appointments, per **individual preventive oral healthcare plan**, and maintain full documentation.
- Ideally, track both oral healthcare results and financial impact over designated periods of time, for example, a three-year timeframe.

Family and Consumer Perspectives: Adults with Developmental Disabilities

Descriptive Findings

The final sample size in the descriptive analysis is 436, based upon surveys completed by respondents. Of a total of 466 surveyed received, 30 cases were removed from analysis because they did not answer any questions beyond the first 6 demographic questions.

Throughout the report of quantitative findings, discussions and charts provide the number of non-respondents, in addition to the relative counts for respondents within each category, for purposes of clarity and consistency.

Of those who completed the survey, 75 (17.2%) completed it themselves, 221 (50.7%) had a family member complete it on their behalf, and 127 (29.1%) had a caregiver complete the survey. A total of 13 (3%) did not answer this question.

Chart 22: Age of Respondents

Age	n	%	Valid %
18-30	184	42.2	42.9
31-40	76	17.4	17.7
41-50	80	18.3	18.6
51-60	59	13.5	13.8
61-70	23	5.3	5.4
> 70	7	1.6	1.6
Total	429	98.4	100.0
No response	7	1.6	
Total	436	100.0	

As shown in Chart 23, responses to the questionnaire by gender indicated a slightly higher percentage of male (51.1%) than female (48.9%) respondents with 4.4% not specifying gender of the consumer.

Chart 23: Respondents to Consumer Survey by Gender

Gender	n	%	Valid %
Male	213	48.9	51.1
Female	204	46.8	48.9
Total	417	95.6	100.0
No response	19	4.4	

Chart 24 summarizes the ethnicity of consumer respondents. As noted below, the majority of participants were White/Non-Hispanic (63.3%). A total of 6 (1.4%) participants did not answer this question.

Chart 24: Respondents to Consumer Survey by Ethnicity

Ethnicity	n	%	Valid %
Hispanic	91	20.9	21.2
White, Non-Hispanic	276	63.3	64.2
African-American	21	4.8	4.9
Native American	35	8.0	8.1
Asian	7	1.6	1.6
Total	430	98.6	100.0
No response	6	1.4	
Total	436	100.0	

Location of residence was indicated for consumers who completed the survey. As shown in Chart 25, the majority of participants live in either Phoenix or Tucson (41.5%). A total of 18 (4.1%) indicated they live in a tribal community. A total of 3 (0.7%) did not answer this question.

Chart 25: Location of Consumer Residence

City	n	%	Valid %
Phoenix	90	20.6	20.8
Tucson	91	20.9	21.0
Glendale	26	6.0	6.0
Mesa	22	5.0	5.1
Chandler	10	2.3	2.3
Scottsdale	13	3.0	3.0
Flagstaff	5	1.1	1.2
Yuma	14	3.2	3.2
Casa Grande	21	4.8	4.8
Nogales	2	.5	.5
Winslow	2	.5	.5
Queen Creek	2	.5	.5
Safford	5	1.1	1.2
Tolleson	2	.5	.5
Gilbert	14	3.2	3.2
Tempe	10	2.3	2.3
Goodyear	3	.7	.7
Apache Junction	3	.7	.7
Prescott	4	.9	.9
Peoria	10	2.3	2.3
Bisbee	2	.5	.5
Buckeye	2	.5	.5
Bullhead	2	.5	.5
Coolidge	3	.7	.7
Cottonwood	3	.7	.7
Douglas	3	.7	.7
Fountain Hills	2	.5	.5
Globe	2	.5	.5
Gold Canyon	2	.5	.5
Lake Havasu	5	1.1	1.2
Payson	4	.9	.9
Lakeside	3	.7	.7
Prescott Valley	2	.5	.5
Sierra Vista	5	1.1	1.2
Sun City/ Sun City West	2	.5	.5
Surprise	2	.5	.5
Tribal community	18	4.1	4.2
Other City or Town	22	5.0	5.1
Total	433	99.3	100.0
No Response	3	.7	
Total	436	100.0	

Of the 18 participants who indicated that they lived in a Tribal Community, 6 (33.3%) lived in the Navajo Nation.

Chart 26: Tribal Community Residence of Respondents

Tribal Community	n	%
Cocopah Tribe of Arizona	1	5.6
Gila River Indian Community	1	5.6
Havasupai Tribe	1	5.6
Hopi Tribe of Arizona	1	5.6
Navajo Nation	6	33.3
Pascua Yaqui Tribe	1	5.6
Salt River Pima-Maricopa Indian Community	2	11.1
San Carlos Apache Tribe	1	5.6
Tohono O'odham Nation	1	5.6
White Mountain Apache Tribe	2	11.1
Yavapai-Prescott Tribe	1	5.6
Total	18	100.0

The majority of participants (56.4%) indicated that they live with family members. Ten (2.3%) did not answer this question.

Chart 27: Residential Living Arrangement of Consumer Respondents

Housing	n	%	Valid %
Independently	56	12.8	13.1
In a supported living arrangement or college dormitory	7	1.6	1.6
With family	246	56.4	57.7
In a group home or foster home	113	25.9	26.5
In an intermediate care facility (ICF/MR)	4	.9	.9
Total	426	97.7	100.00
No response	10	2.3	
Total	436	100.0	

As shown on Chart 28, the majority of participants (64.3%) completed some form of high school education, with 200 (45.9%) receiving a diploma, 74 (17%) receiving a certificate of high school completion and 6 (1.4%) completing the GED. A total of 66 (15.1%) did not answer this question.

Chart 28: High School Education of Consumer Respondents

High School Education	n	%	Valid %
High School Diploma	200	45.9	54.1
General Education Development (GED)	6	1.4	1.6
Certificate of High School Completion	74	17.0	20.0
Did not complete High School	90	20.6	24.3
Total	370	84.9	100.0
No response	66	15.1	
Total	436	100.0	

As shown in Chart 29, of the 80 respondents who indicated having some form of post-secondary education, 24 (30%) completed a BA/BS degree. A total of 24 (30%) indicated they were currently attending school.

Chart 29: Postsecondary Education of Consumer Respondents

Post-Secondary Education	n	%
Currently attending non-traditional educational program	24	30.0
Post-Secondary Vocational Certificate	11	13.8
Associate of Arts or Science	11	13.8
Bachelor's Degree (BA, BS)	24	30.0
Master's Degree (MA, MS)	8	10.0
Doctoral Degree (PhD or EDD)	2	2.5
Total	80	100.0

Chart 30 summarizes reported sources of income by survey respondents. The majority (63.8%) of participants indicated they received Social Security alone. A total of 55 (12.6%) reported multiple sources of income. A total of 27 (6.2%) did not respond to this question.

Chart 30: Sources of Income Reported by Consumers

Income	n	%	Valid %
Social Security(SS)	278	63.8	68.0
Disability	27	6.2	6.6
Work/Pay	49	11.2	12.0
SS and Disability	21	4.8	5.1
SS and Work/Pay	26	6.0	6.4
Disability and Work/Pay	1	.2	.2
SS, Disability, and Work/Pay	7	1.6	1.7
Total	409	93.8	100.0
No response	27	6.2	
Total	436	100.0	

As shown in Chart 31, the majority of participants (71.8%) indicated that they did not volunteer. A total of 21 (4.8%) did not answer this question.

Chart 31: Reported Number of Volunteers by Survey Respondents

Volunteer	n	%	Valid %
Yes	102	23.4	24.6
No	313	71.8	75.4
Total	415	95.2	100.0
No response	21	4.8	
Total	436	100.0	

The majority of participants (70.6%) indicated they are not employed at a paying job. A total of 25 (5.7%) did not respond to this question.

Chart 32: Reported Employment by Survey Respondents

Employed	n	%	Valid %
Yes	103	23.6	25.1
No	308	70.6	74.9
Total	411	94.3	100.0
No response	25	5.7	
Total	436	100.0	

As noted in Chart 33, of the 103 who reported having a paying job, 35 (34%) indicated they receive dental benefits from their employer. A total of 3 (2.9%) did not answer the question.

Chart 33: Reported Dental Benefits by Consumers Who Are Employed

Dental Benefits from Employer	n	%	Valid %
Yes	35	34.0	35.0
No	65	63.1	65.0
Total	100	97.1	100.0
No Response	3	2.9	
Total	103	100.0	

As indicated in Chart 34, the majority of participants (48.9%) reported having coverage from AHCCCS, followed by 26.8% having coverage from ALTCS. A total of 28 (6.4%) did not answer this question.

Chart 34: Type of Medical Insurance Coverage Reported by Respondents

Medical Insurance	n	%	Valid %
AHCCCS (Arizona Health Care Cost Containment System)	213	48.9	52.2
ALTCS (Arizona Long-Term Care System)	117	26.8	28.7
Medicare	32	7.3	7.8
Private Medical Insurance	46	10.6	11.3
Total	408	93.6	100.0
No response	28	6.4	
Total	436	100.0	

In Chart 35, the majority of participants (43.3%) indicating not having any dental insurance. A total of 23 (5.3%) did not answer this question.

Chart 35: Dental Insurance Reported by Respondents

Dental Insurance	n	%	Valid %
Public (Medicare/Medicaid/AHCCCS)	133	30.5	32.2
Private (from a private carrier)	91	20.9	22.0
None	189	43.3	45.8
Total	413	94.7	100.0
No Response	23	5.3	
Total	436	100.0	

The majority of participants (53.2%) have not had any teeth removed. A total of 120 (27.5%) have had 1 to 5 permanent teeth removed. A total of 31 (7.1%) did not answer this question.

Chart 36: Number of Teeth Removed

Number of Teeth Removed	n	%	Valid %
1 to 5 removed	120	27.5	29.6
6 or more, but not all, removed	42	9.6	10.4
All removed	11	2.5	2.7
None removed	232	53.2	57.3
Total	405	92.9	100.0
No Response	31	7.1	
Total	436	100.0	

The majority of participants (54.2%) indicated having all of his/her teeth. A total of 23 (5.3%) participants did not answer the question.

Chart 37: Reported Number of Participants Who Have All of their Teeth

Have All Teeth	n	%	Valid %
Yes	224	51.4	54.2
No	189	43.3	45.8
Total	413	94.7	100.0
No response	23	5.3	
Total	436	100.0	

In Chart 38, only 16 participants (3.7%) reported having no teeth. A total of 79 (18.1%) participants did not answer this question.

Chart 38: Participants Who Reported Being Without Teeth

No Teeth	n	%	Valid %
Yes	16	3.7	4.5
No	341	78.2	95.5
Total	357	81.9	100.0
No response	79	18.1	
Total	436	100.0	

As shown in Chart 39, only 12 (2.8%) participants reported wearing dentures. A total of 234 (53.7%) did not answer this question.

Chart 39: Participants Who Reported Wearing Dentures

Dentures	n	%	Valid %
I do not wear dentures.	190	43.6	94.1
I wear partial dentures (upper or lower).	12	2.8	5.9
Total	202	46.3	100.0
No response	234	53.7	
Total	436	100.0	

In response to a question about the condition of their mouth and teeth, 56.6% reported “fair” to “good.” A total of 29 (6.7%) did not answer this question.

Chart 40: Reported Condition of Participants' Mouth and Teeth

Condition of Mouth/Teeth	n	%	Valid %
Very good	57	13.1	14.0
Good	120	27.5	29.5
Fair	127	29.1	31.2
Poor	96	22.0	23.6
Don't know	7	1.6	1.7
Total	407	93.3	100.0
No response	29	6.7	
Total	436	100.0	

The majority of participants (57.3%) rated their gums as fair to good. A total of 29 (6.7%) did not answer this question. It should be noted that self-reported assessments of one's gums should be interpreted with caution, based upon potentially greater emphasis being placed upon the condition of respondents' teeth, versus gums, and on the level of knowledge required to determine condition of the gums.

Chart 41: Reported Condition of Participants' Gums

Condition of Gums	n	%	Valid %
Very good	57	13.1	14.0
Good	127	29.1	31.2
Fair	123	28.2	30.2
Poor	88	20.2	21.6
Don't know	12	2.8	2.9
Total	407	93.3	100.0
No response	29	6.7	
Total	436	100.0	

Respondents were asked to specify all oral health problems that applied to them. A total of 915 problems were endorsed. Frequencies and percentages furnish information regarding the extent of known problems versus those not known.

Chart 42: Reported Oral Healthcare Problems

Dental Problems	Frequency	%
Pain	65	15.6
Cavities	125	29.9
Broken Teeth	64	15.3
Crooked Teeth	86	20.5
Teeth Need Cleaning	206	49.3
Gum Problems	137	32.8
Grinding Teeth	71	17
Root Canal/Nerve Problems	39	9.3
No Problems	91	21.8
Don't know	31	7.4

Note: 18 participants did not provide a response to this question. Percentages are calculated as the frequency endorsed out of 418. Thus, of the 418 participants who provided a response to this question, 29.9% reported cavities.

As shown in Chart 43, of the 296 participants who indicated at least one dental problem, a total of 215 (72.6%) reported more than one. The average number of dental problems was 1.89 (sd = 1.1).

Chart 43: Oral Healthcare Problem by Multiples Reported

Number of Dental Problems	N	%
1	81	27.4
2	83	28.0
3	58	19.6
4	38	12.8
5	14	4.7
6	9	3.0
7	8	2.7
8	5	1.7
Total	296	100.0

Chart 44 specifies all problems experienced by respondents during the past six months. Participants were asked to check all of the problems that applied to their situation.

Chart 44: Reported Dental Problems during the Recent Six-Month Period

Problems in Past 6 months	Frequency	%
Difficulty eating or chewing	61	15.3
Difficulty eating solid food	42	10.6
Difficulty swallowing	29	7.3
Bleeding gums	95	23.9
Mouth pain	65	16.3
Mouth sores	33	8.3
Loose teeth not due to injury	31	7.8
Loose teeth due to injury	2	0.5
Decayed teeth	68	17.1
Broken or missing fillings	32	8.0
Dry mouth	50	12.6
Bad breath	112	28.1
No problems	164	41.2

Note: 38 participants did not respond to this question. Percentages are calculated as the frequency endorsed out of 398. Thus, of the 398 participants who answered this question, 15.3% reported difficulty eating or chewing.

Of the 234 respondents who indicated at least one problem over the last 6 months, 152 (65%) reported more than one problem. The average number of problems reported was 1.56 (SD = 1.9).

Chart 45: Oral Healthcare Problems during the Recent Six-Month Period by Multiples Reported

Number of Dental Problems in Past 6 months	n	%
1	82	35.0
2	48	20.5
3	38	16.2
4	38	16.2
5	13	5.6
6	3	1.3
7	6	2.6
8	3	1.3
9	3	1.3
Total	234	100.0

As shown in Chart 46, a total of 76 (17.4%) respondents indicated that they had a problem with their teeth or gums that made it painful to eat. A total of 46 (10.6%) did not answer this question.

Chart 46: Reported Pain Experienced during Eating

Pain During Eating	n	Percent	Valid %
Yes	76	17.4	19.5
No	314	72.0	80.5
Total	390	89.4	100.0
No response	46	10.6	
Total	436	100.0	

Chart 47 summarizes the specific difficulties participants had in the dentist chair. Problems specified confirm the types of challenges that consumers experience, in addition to the support requirements for dental practitioners to mitigate the difficulties for patients.

Chart 47: Reported Difficulties in Dentist Chair

Difficulties in Dentist Chair	Frequency	%
Difficulty sitting still for a long time	153	57.3
Difficulty keeping mouth open for a long time	200	74.9
Difficulty with equipment that holds mouth open	152	56.9
Difficulty with florescent lighting	54	20.2
Difficulty with certain noises	105	39.3
Very afraid of dental work	140	52.4

Note. 169 participants did not endorse any difficulty/problem. This may indicate that these participants did not have any of the listed difficulties, or that they did not respond to the question. Percentages are thus calculated from the 267 that endorsed at least one difficulty/problem in the dentist chair. For example, of the 267 participants that endorsed at least one difficulty, 57.3% indicated they had difficulty sitting still for a long time.

As indicated in Chart 48, of the 267 respondents that indicated at least one difficulty in the dentist chair, 195 (73%) reported having more than 1 difficulty. The average number of difficulties was 1.84 (SD = 2).

Chart 48: Difficulties in Dentist Chair by Multiples Reported

Number of Difficulties in Dentist Chair	n	%
1	72	27.0
2	55	20.6
3	30	11.2
4	46	17.2
5	36	13.5
6	28	10.5
Total	267	100.0

Chart 49 shows health problems endorsed by respondents. Participants were asked to check all of the health problems that applied to them.

Chart 49: Reported Health Problems of Respondents

Health Problems	Frequency	%
Diabetes	44	31.7
High blood pressure	56	40.3
Heart disease	22	15.8
Breathing difficulty	45	32.4
Contractures	35	25.2

Note: 297 participants did not endorse any health condition. This may indicate that these participants did not have any of the listed health conditions, or that they did not respond to the question. Percentages are thus calculated from the 139 participants who endorsed at least one health condition. Thus, of those respondents who endorsed at least one health problem, 31.7% had diabetes.

As shown on Chart 50, of the 139 respondents who reported at least one health problem, 50 (36%) reported more than one health problem. The average number of health problems reported was .46 (SD = .77)

Chart 50: Number of Health Problems by Multiples Reported

Number of Health Problems	n	%
1	89	64.0
2	38	27.3
3	11	7.9
4	1	.7
Total	139	100.0

As shown in Chart 51, the highest percentage of participants (28.9%) reported that they are able to brush their teeth by themselves. A total of 42 (9.6%) did not answer this question.

Chart 51: Level of Ability in Caring for Teeth

Caring for Teeth	n	Percent	Valid %
By myself, I brush my teeth very well	126	28.9	32.0
With difficulty: It is hard for me to brush appropriately by	55	12.6	14.0
With assistance of a caregiver	100	22.9	25.4
A caregiver must do this for me	113	25.9	28.7
Total	394	90.4	100.0
No response	42	9.6	
Total	436	100.0	

The majority of participants (49.5%) brush their teeth twice a day. A total of 38 (8.7%) did not respond to this question.

Chart 52: Reported Frequency of Brushing Teeth

How Often Brush Teeth	n	Percent	Valid %
More than 3 times a day	5	1.1	1.3
3 times daily	42	9.6	10.6
2 times daily	216	49.5	54.3
1 time daily	112	25.7	28.1
Less than once a day	23	5.3	5.8
Total	398	91.3	100.0
No response	38	8.7	
Total	436	100.0	

As shown in Chart 53, the majority of participants (51.4%) reported that they never floss their teeth. A total of 46 (10.6%) did not answer this question.

Chart 53: Reported Frequency of Flossing Teeth

How Often Floss	n	Percent	Valid %
More than 3 times a day	1	.2	.3
3 times daily	3	.7	.8
2 times daily	19	4.4	4.9
1 time daily	62	14.2	15.9
Less than once a day	34	7.8	8.7
Once or twice a week	47	10.8	12.1
I never floss my teeth	224	51.4	57.4
Total	390	89.4	100.0
No response	46	10.6	
Total	436	100.0	

Chart 54 shows the different types of dental equipment items endorsed. Participants could endorse more than one type of equipment. The highest number indicated was regular toothbrush, followed by electric toothbrush.

Chart 54: Dental Equipment Reported

Dental Equipment	Frequency	%
Regular toothbrush	249	64.2
Toothbrush with special grip	9	2.3
Electric toothbrush	176	45.4
Toothpaste squeezer	27	7
Toothpaste dispenser	13	3.4
Power or special flosser	10	2.6

Note: 48 participants did not endorse any type of dental equipment. This may indicate that these participants did not have any of the listed type of dental equipment, or that they did not respond to the question. Percentages are thus calculated from the 388 participants who endorsed at least one type of dental equipment/tool. Thus, of the 388 who reported using at least one type of dental tool, 64.2% reported using a regular toothbrush.

As shown in Chart 55, of the 388 who reported owning at least one type of dental tool, 78 (20%) reported owning more than one. The average number of dental tools was 1.11 (SD = 0.68).

Chart 55: Dental Equipment by Multiples Reported

Number of Pieces of Dental Equipment	n	%
1	310	79.9
2	67	17.3
3	8	2.1
5	2	.5
6	1	.3
Total	388	100.0

The majority of participants (56.0%) reported visiting a dentist within the last year. The 12 months preceding the administration of the survey in June, 2011 means that until the October 2010 change in state funding, participants would have had oral healthcare coverage for a portion of the preceding 12-month period. Thus, greater than half of respondents reported having seen the dentist in the past year. A total of 38 respondents (8.7%) did not answer this question.

Chart 56: Time of Most Recent Dental Visit Reported

Time of Last Dentist Visit	n	Percent	Valid %
Within the past year (any time less than 12 months ago)	244	56.0	61.3
Within the past 2 years (more than1 year but less than 2 years ago)	71	16.3	17.8
Within the past 5 years (more than2 years but less than 5 years ago)	45	10.3	11.3
5 or more years ago	35	8.0	8.8
Never	3	.7	.8
Total	398	91.3	100.0
No response	38	8.7	
Total	436	100.0	

As shown in Chart 57, most participants (55%) reported seeing the same dentist as their previous visit. A total of 51 respondents (11.7%) did not answer this question.

Chart 57: Whether Consumer Saw the Same Dentist at Recent Visit

Do you see the same dentist?	n	Percent	Valid %
Yes, I see the same dentist.	240	55.0	62.3
No, I do not see the same dentist.	102	23.4	26.5
I once visited a dentist and I did not go back	41	9.4	10.6
I have never visited a dentist	2	.5	.5
Total	385	88.3	100.0
No response	51	11.7	
Total	436	100.0	

The most frequently reported reasons (of the total reported reasons indicated) for visiting the dentist were teeth cleaning and dental checkup.

Chart 58: Reported Reasons for Most Recent Visit to the Dentist

Reasons for Last Dentist Visit	Frequency	%
Dental check-up	224	58
Teeth cleaning	242	62.7
Tooth filling	61	15.8
To have teeth pulled or other surgery	61	15.8
Toothache	37	9.6
Fix dentures	11	2.8
Have dentures made	7	1.8
Get a prescription	3	0.8
Bleeding gums/ periodontal disease	32	8.3
Loose teeth	8	2.1
Problems with wisdom teeth	12	3.1
Don't know	15	3.9

Note: 50 participants did not respond to this question. This may indicate that these participants did not have any of the problems listed, or that they did not respond to the question. Percentages are thus calculated from the 386 participants who endorsed any of the listed problems/reasons for going to the dentist (including the "don't know" option). Thus, of the 386 who responded to this question, 58% reported a regular check-up as a reason for their last visit.

As shown in Chart 59, of the 371 who indicated at least one reason for the most recent dental visit, 226 (61%) reported more than one reason for the last visit. The average number of reasons for the last visit was 1.6 (SD = 1.07).

Chart 59: Reasons for Last Dentist Visit by Multiples Reported

Reasons for Last Dentist Visit	n	%
1	145	39.1
2	153	41.2
3	50	13.5
4	18	4.9
5	5	1.3
Total	371	100.0

As shown in Chart 60, the most frequently cited reasons for not going to the dentist were no money to pay for dental care (70%) and no dental insurance (59%).

Chart 60: Reasons for Not Going to the Dentist

Reasons for Not Going to Dentist	Frequency	%
On a wait list for dentist	16	7.4
No transportation	6	2.8
No dentist close to participant	10	4.6
No money to pay for dental care	152	70
No dental insurance	128	59
Concern about discomfort or pain	28	12.9
No one available to go with participant	9	4.1
Fear of dentist	38	17.5

Note: 219 participants did not respond to this question. This may indicate that these participants did not have any of the problems listed, or that they did not respond to the question. Percentages are thus calculated from the 217 participants who endorsed any of the listed reasons for NOT going to the dentist. Thus, of the 217 who endorsed at least one reason for not going to the dentist, 7.4% reported being on a wait list.

As shown in Chart 61, of the 217 respondents who indicated at least one reason for not going to the dentist, 118 (54.4%) reported more than one reason. The average number of reasons was .89 (SD = 1.1).

Chart 61: Reasons for Not Going to the Dentist by Multiples Reported

Number of Reasons for Not Going to Dentist	n	%
1.00	99	45.6
2.00	82	37.8
3.00	24	11.1
4.00	10	4.6
5.00	1	.5
7.00	1	.5
Total	217	100.0

The majority of participants (49.1%) reported having had a teeth cleaning within the past year. The 12 months preceding the administration of the survey in June, 2011 means that until the October 2010 change in state funding, participants would have had oral healthcare coverage for a portion of the preceding 12-month period. Thus, nearly half of respondents reported having had their teeth cleaned in the past year. A total of 45 (10.3%) did not answer this question.

Chart 62: Time of Most Recent Teeth Cleaning

Time of Last Teeth Cleaning	n	Percent	Valid %
Within the past year (any time less than 12 months ago)	214	49.1	54.7
Within the past 2 years (more than 1 year but less than 2 ye	76	17.4	19.4
Within the past 5 years (more than 2 years but less than 5 ye	47	10.8	12.0
5 or more years ago	40	9.2	10.2
Never	14	3.2	3.6
Total	391	89.7	100.0
No response	45	10.3	
Total	436	100.0	

Chart 63 cites the reasons for visiting the dentist or dental hygienist the most recent time. The most frequently cited reason was teeth cleaning.

Chart 63: Reason for Most Recent Visit with Dentist/Dental Hygienist

Reason for Last Visit with Dentist/Dental Hygienist	Frequency	%
Teeth Cleaning	254	71.3
Stained, yellow, or blackened teeth	30	8.4
Fluoride treatment	36	10.1
Gum problems	61	17.1
Regular preventive care	146	41
Don’t know	37	10.4

Note: 80 participants did not endorse any of the reasons. This may indicate that these participants did not have any of the problems listed, or that they did not respond to the question. Percentages are thus calculated from the 356 participants who endorsed any of the listed problems/reasons for going to the dentist/hygienist the last time (including the “don’t know” option). Thus, of the 356 who responded to this question, 71.3% reported a teeth cleaning as a reason for their last visit.

Of the 319 who reported a reason for the last visit with a dental hygienist, 141 (44%) reported more than one reason. The average number of reasons was 1.21 (SD = 1.05).

Chart 64: Reasons for Most Recent Visit to Dentist/Dental Hygienist by Multiples Reported

Number of Reasons for Last Dentist/Hygienist Visit	n	%
1	178	55.8
2	91	28.5
3	37	11.6
4	9	2.8
5	4	1.3
Total	319	100.0

As shown in Chart 65, most participants (55.5%) have never been to the ER for a dental reason. A total of 143 (32.8%) did not answer this question.

Chart 65: Time of Most Recent ER Visit for Dental Reason

Time of Last ER Visit for Dental Reason	n	Percent	Valid %
Within the past year (any time less than 12 months ago)	9	2.1	3.1
Within the past 2 years (More than1 year but less than 2 years)	10	2.3	3.4
Within the past 5 years (More than2 years but less than 5 years)	10	2.3	3.4
5 or more years ago	22	5.0	7.5
Never	242	55.5	82.6
Total	293	67.2	100.0
No response	143	32.8	
Total	436	100.0	

Chart 66 indicates reasons for visiting the emergency room for oral healthcare reasons. Of those who indicated at least one reason for their last ER visit, the most frequently cited reasons were mouth pain, difficulty or discomfort eating solid food, and decayed teeth.

Chart 66: Reported Reasons for Most Recent Emergency Room Visit for Dental Reason

Reason for Last ER Visit (Dental)	Frequency	%
Difficulty or discomfort eating or chewing	11	27.5
Difficulty or discomfort eating solid food	6	15
Difficulty or discomfort swallowing	5	12.5
Bleeding gums	4	10
Mouth Pain	20	50
Mouth sores	5	12.5
Loose teeth not due to injury	5	12.5
Loose teeth due to injury	7	17.5
Decayed teeth	11	27.5
Broken or missing fillings	7	17.5

Note: Of the 51 participants who indicated ever having gone to the ER for dental care, a total of 40 indicated at least one reason for their last ER visit. Thus, percentages are calculated from the 40 participants who reported at least one reason for their last ER visit. Of the 40 participants who endorsed at least one reason for their visit to the ER, 27.5% reported difficulty eating or discomfort eating or swallowing.

As shown in Chart 67, of the 40 survey participants who reported a reason for their last ER visit, 18 (45%) reported more than one reason. Of those who indicated ever going to the ER for dental reasons, the average number of reasons for their last visit was 2.0 (SD = 1.5).

Chart 67: Reasons for Most Frequent Visit to Emergency Room by Multiples Reported

Number of reasons for last visits to ER	n	%
1	22	55.0
2	7	17.5
3	4	10.0
4	4	10.0
5	2	5.0
6	1	2.5
Total	40	100.0

Of the 51 respondents who indicated they had been to the Emergency Room for a dental reason, most (39.2%) were referred to a dentist. A total of 20 (39.2%) did not answer this question.

Chart 68: Reported Outcome of Emergency Room Visit

ER Outcome	N	Percent	Valid %
I was hospitalized	5	9.8	16.1
I was referred to a dentist	20	39.2	64.5
I was prescribed medication	6	11.8	19.4
Total	31	60.8	100.0
No response	20	39.2	
Total	51	100.0	

Statistical Findings: Significant Differences by Age Relative to Dental Health Items

Statistical analyses were performed relative to age of respondents to determine significant differences regarding dental health items. In the following section of the report, only significant correlations are reported. Spearman's rho measures the relationship between two variables, based upon linearity. It differs from Pearson's correlation in that computations are performed after the numbers have been converted to ranks.

Chart 69 shows correlations of survey items according to age. A positive correlation means that older participants are more likely to respond "yes" than younger participants. A negative correlation means that younger participants are more likely to respond "yes" than older participants.

Chart 69: Significant Differences by Age on Items Related to Oral Health

Question	Spearman's rank correlation	Interpretation
Q16: The number of my permanent teeth removed because of tooth decay or gum disease is: (0 = None, 1 = 1 to 5, 2 = 6 +, but not all, 3 = all)	r = .33, p < .001	Older participants have had more permanent teeth removed than younger participants
Q17: I have all of my teeth:	r = -.226, p < .01	Younger participants are more likely to have all their teeth
Q18: I have no teeth:	r = .265, p < .01	Older participants are more likely to indicate having no teeth
Q19: I wear dentures	r = .165, p < .05	Older participants are more likely to have dentures

Q20:I would describe the condition of my mouth and teeth as: (poor = 1 very good = 4) (poor = 1 very good = 4)	r = -.170, p < .01	Younger participants rated their teeth in better condition than older participants
Q21:I would describe the condition of my gums as: (poor = 1 very good = 4)	r = -.119, p < .05	Younger participants rated their gums in better condition than older participants
Q22-3: Broken or missing teeth that impair my ability to eat	r = .165 , p < .01	Older participants reported more broken or missing teeth than younger participants
Q22-5: Teeth that need cleaning	r = - .126, p < .05	Younger participants reported needing more teeth cleaning than older participants
Q23-1: Past 6 months: Difficulty eating or chewing	r = .152, p < .01	Older participants reported more difficulty eating or chewing in the past 6 months than younger participants
Q23-12: Past 6 months: Bad Breath	r = -.172 , p < .01	Younger participants reported bad breath more than older participants
# of dental problems during last 6 months (Note: a variable was created representing the sum of the number of problems during the past 6 months each participant reported, because respondents could choose more than one dental problem.)	r = .119, p < .05	The total number of dental problems in the past 6 months per participant increased with age.
Q25-1: The following situations apply to me in the dentist chair: I have difficulty sitting still for a long time	r = -.179, p < .01	Younger participants reported difficulty sitting still for a long time more than older participants
Q25-2: The following situations apply to me in the dentist chair: I have difficulty keeping my mouth open for a long time	r =-.204, p < .01	Younger participants reported difficulty keeping their mouths open for a long time more than older participants
Q25-3: The following situations apply to me in the dentist chair: I have difficulty with equipment that holds my mouth open	r = -.167, p < .01	Younger participants reported difficulty with equipment that holds the mouth open more than older participants
Q25-5: The following situations apply to me in the dentist chair: I have difficulty with certain noises	r = -.162, p < .01	Younger participants reported difficulty with certain noises more than older participants
# of Difficulties in dentist chair (Note: Based upon the sum of difficulties reported per participant, for purposes of analysis.)	r = -.191, p < .001	The total number of difficulties in the dentist chair decreased with age (younger participants reported greater number of difficulties)
Q26-1: Health conditions: Diabetes	r = -.21, p < .001	Older participants reported having diabetes more often than younger participants
Q26-2: Health conditions: High blood pressure	r = .26, p < .001	Older participants reported high blood pressure more often than younger participants
# of Health conditions (Note: based upon the sum of the number of difficulties reported per participant.)	r = .21, p < .001	The total number of health conditions reported increased with age (older participants reported greater number of health conditions)

Q27: I am able to care for my teeth: (1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me)	r = -.125, p < .05	Increased age was associated with more independence in caring for teeth
# of tools (Note: based upon the sum of the number of responses to the question “types of dental tools/equipment used)	r = -.15, p < .001	The total number of dental tools decreased with age (younger participants have more dental tools)
Q33-1: Reason for last dentist visit: Regular check-up	r = -.211, p < .001	Younger participants reported a regular check-up as a reason for visiting the dentist the last time more often than older participants
Q33-2: Reason for last dentist visit: Teeth cleaned	r = -.133, p < .01	Younger participants reported getting teeth cleaned as a reason for visiting the dentist the last time more often than older participants
Q33-6: Reason for last dentist visit: Adjust or repair denture	r = .145, p < .01	Older participants reported getting dentures adjusted or repaired as a reason for visiting the dentist the last time more often than younger participants
Q33-7: Reason for last dentist visit: Have denture made	r = .133, p < .01	Older participants reported having dentures made as a reason for visiting the dentist the last time more often than younger participants
# of reasons for last dentist visit: (Note: based upon the sum of the number of reasons for most recent dental visit.)	r =-.13, p < .01	Total number of reasons for visiting the dentist last time decreased with age.
Q34-7: Stopped me from going to dentist: Need someone to go with me, no one available	r =.128, p < .01	Older participants reported needing someone to go with them to the dentist and having no one available as a reason for not going to the dentist more often than younger participants
Q36-1: Reason for last visit to dentist/ hygienist: Regular cleaning	r = -.189, p < .01	Younger participants reported getting regular cleaning as a reason for visiting the dentist/hygienist the last time more often than older participants
Q36-3: Reason for last visit to dentist/ hygienist: Fluoridation treatment	r = -.164, p < .01	Younger participants reported getting fluoride treatment as a reason for visiting the dentist/hygienist the last time more often than older participants
Q36-5: Reason for last visit to dentist/ hygienist: Regular preventative care	r = -.100, p < .05	Younger participants reported getting regular preventive care as a reason for visiting the dentist/hygienist the last time more often than older participants
Number of reasons for last visit to dentist/hygienist: (Note: Based upon the number of reasons for going to the dentist/hygienist.)	r = -.162, p < .001	Total number of reasons for visiting dentist/dental hygienist decreased with age.
Q38-7: Reason for last ER visit : Loose teeth not due to injury	r =.298, p < .05	Older participants were more likely to report loose teeth (not due to injury) as the reason for visiting the ER more often than younger participants

Statistical Findings: Significant Differences by Gender Relative to Dental Health Items

In the following section, differences between males and females were analyzed. Significant differences are reported in the charts that follow in this section of the report. (Note: Male = 1 Female = 2). For ease of interpretation, odds ratios were calculated with the highest “positive endorsement” group as the reference group.

Tests were performed using chi-square, a statistical test used to compare whether there is a significant difference between observed and expected results. Using the null hypothesis, it might be expected that, proportionally, male and female responses would be equal. Where significant differences were noted, results are reported below.

As shown in Chart 70, female participants were more likely to report having cavities than males (marginally significant at p = .06). This information may have utility for caregivers and dental professionals in ensuring adequate preventive and treatment care for consumers.

Chart 70: Cavities by Gender

	No	Yes
Male	104 (55.9%)	52 (44.8%)
Female	82 (44.1%)	64 (55.2%)
	100%	100%

Chi-square (1) = 3.516, p = .06
Odds ratio = 1.56

Female participants were 1.56 times more likely to report having cavities than males.

As indicated in Chart 71, females were more likely than males to report root canal or nerve problems with their teeth.

Chart 71: Root Canal or Nerve Problem by Gender

	No	Yes
Male	142 (54%)	14 (35.9%)
Female	121 (46%)	25 (64.1%)
	100%	100%

Chi-square (1) = 4.45, p = .04
Odds Ratio = 2.10

Female participants were 2.1 times more likely to report having a root canal or nerve problems than males.

During the past 6 months, I have had the following problems that lasted more than a day:

Chart 72: Bad Breath by Gender

	No	Yes
Male	66 (42.6%)	67 (63.8%)
Female	89 (57.4%)	38 (36.2%)
	100%	100%

Chi-square(1) = 11.29, p < .001
Odds Ratio = 2.37

Male participants were 2.37 times more likely to report having bad breath over the past 6 months than females.

Chart 73 indicates that males were more likely than females to report having difficulty sitting still for a long time.

Chart 73: Difficulty Sitting Still for a Long Time by Gender

	No	Yes
Male	127 (46.9%)	86 (58.1%)
Female	144 (53.1%)	60 (41.1%)
	100%	100%

Chi-square(1) = 5.51, p = .02
Odds Ratio = 1.62

Male participants were 1.62 times more likely to report difficulty sitting still for a long time than female participants.

As shown in Chart 74, males were more likely than females to report having difficulty with equipment that holds open the mouth.

Chart 74: Difficulty with Equipment that Holds the Mouth Open by Gender

	No	Yes
Male	128 (47.1%)	85 (58.6%)
Female	144 (52.9%)	60 (41.4%)
	100%	100%

Chi-square (1) = 5.06, p = .02
Odds Ratio = 1.57

Male participants were 1.57 times more likely to report having difficulty with the equipment that holds open the mouth than female participants.

As noted in Chart 75, female respondents were more likely than males to have a history of contractures (the shortening or hardening of muscles that leads to rigidity).

Chart 75: History of Contractures by Gender

	No	Yes
Male	198 (52.7%)	15 (36.6%)
Female	178 (47%.3)	26 (63.4%)
	100%	100%

Chi-square (1) = 3.82, p = .05
Odds Ratio = 1.93

Female participants were 1.93 times more likely to have a history of contractures.

Chart 76 indicates that males were more likely than females to report “regular checkup” as the reason for their most recent visit to the dentist.

Chart 76: Regular Check-up as Reason for Most Recent Dental Visit by Gender

	No	Yes
Male	85 (45%)	122 (57.3%)
Female	104 (55%)	91 (42.7%)
	100%	100%

Chi-square(1) = 6.07, p = .01
Odds ratio: 1.64

Male participants were 1.64 times more likely to have reported having a regular check-up as the reason for their last dentist visit than females.

As shown in Chart 77, females were more likely than males to report “to have teeth pulled or other surgery” as their reason for the most recent visit to the dentist.

Chart 77: Having Teeth pulled or Other Surgery as Reason for Most Recent Dental Visit by Gender

	No	Yes
Male	185 (53.6%)	22 (38.6%)
Female	160 (46.4%)	35 (61.4%)
	100%	100%

Chi-square (1) = 4.42, p = .04
Odds Ratio: 1.84

Female participants were 1.84 times more likely report having teeth pulled or other surgery as the reason for their last visit to the dentist.

Chart 78 indicates that female respondents were more likely than their male counterparts to report having dentures made as the reason for their most recent dental visit.

Chart 78: To have a Denture Made as Reason for Most Recent Dental Visit by Gender

	No	Yes
Male	206 (52.2%)	1 (14.3%)
Female	189 (48.8%)	6 (85.7%)
	100%	100%

Chi-square (1) = 3.95, p = .05
Odds Ratio: 6.54

Female participants were 6.54 times more likely to report having dentures made as the reason for their last dentist visit.

Findings for Chart 79 include only those participants who indicated that they had used the Emergency Room for dental care. Female respondents were prescribed medication or referred to the dentist more often than males.

Chart 79: Outcome of Visit to the Emergency Room by Gender

	I was hospitalized	I was referred to a dentist	I was prescribed medication
Male	4 (80%)	4 (20%)	1 (16.7%)
Female	1 (20%)	16 (80%)	5 (83.3%)
	100%	100%	100%

Chi-square(2) = 7.54, p = .02

Female participants were prescribed medication or referred to the dentist more often than males.

In Chart 80, three different significant differences between males and females regarding dental practices are noted. Males reported greater independence than females in caring for their teeth. Males also indicated more recent teeth cleaning than did their female counterparts. Finally, females reported a greater number of reasons for visiting the Emergency Room for dental reasons than did males.

Chart 80: Differences between Males and Females Regarding Reported Dental Practices

Question	Spearman's rank correlation	Interpretation
Q27: I am able to care for my teeth: (1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me)	r = -.14, p < .01	Males reported greater independence than females
Q35: The last time I had my teeth cleaned by a dentist/hygienist was: (1 = within past year, 2 = within past 2 years, 3 = within past 5 years, 4 = 5 or more years ago)	r = .13, p < .01	Males had a teeth cleaning more recently than females
# of reasons for visiting the ER the last time	r = .112, p < .05	Females reported a greater number of reasons for visiting the ER last time than males

Statistical Findings: Significant Differences Relative to Income

Significant differences by income on dental health Items. Here, only significant chi-squares and ANOVAs are reported. Tukey's HSD post-hoc tests were conducted for significant ANOVAs. Percentages in chi-square tables are shown to reflect within-group breakdown.

Chart 81 shows the means and deviations for responses to the question about self-perceived condition of the mouth and teeth.

Chart 81: Self-Described Condition of Mouth and Teeth

Income Source	n	Mean	Std. Deviation
Social Security	266	2.28	.98
Disability	25	1.93	1.0
Work/pay	42	2.89	.97
Combination of 3	52	2.45	1.0
Total	385	2.35	

In response to the question: "I would describe the condition of my mouth and teeth" as:
(poor = 1, very good = 4) (Note: Does not include "don't know"). An analysis of variance was conducted to examine the difference between the overall rating of condition of teeth between the 4 different sources of income. There was a significant difference among the 4 means ($F(3, 384) = 6.29$, $p < .001$). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly higher ratings of the condition of their teeth ($M = 2.89$, $sd = .97$) than those who received Social Security ($M = 2.28$, $sd = .98$) or Disability ($M = 1.93$, $sd = 1.0$).

Chart 82: Analysis of Variance – Self-Described Condition of Mouth and Teeth

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	18.258	3	6.086	6.293	.000
Within Groups	368.485	381	.967		
Total	386.743	384			

Chart 83 shows the means and deviations for responses to the question about self-perceived condition of the gums.

Chart 83: Self-Described Condition of Gums

Income Source	n	Mean	Std. Deviation
Social Security	262	2.30	.97
Disability	25	1.96	.93
Work/pay	42	3.02	.87
Combination of 3	52	2.50	.98
Total	381	2.38	

In response to the question: In response to the question: "I would describe the condition of my gums" as: (poor = 1, very good = 4) (Note: Does not include "don't know"). An analysis of variance was conducted to examine the difference between the overall rating of condition of gums between the 4 different sources of income. There was a significant difference among the 4 means ($F(3, 380) = 8.80$, $p < .001$). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly higher ratings of the condition of their gums ($M = 3.02$, $sd = .87$) than those who received Social Security ($M = 2.30$, $sd = .97$), Disability ($M = 1.96$, $sd = .93$), and the group that had some combination of the 3 ($M = 2.50$, $sd = .98$).

Chart 84: Analysis of Variance – Self-Described Condition of Gums

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	24.338	3	8.113	8.796	.000
Within Groups	347.715	377	.922		
Total	372.052	380			

(poor = 1, very good = 4)

Chart 85 shows the means and standards deviations for responses to the question regarding whether respondents' teeth need cleaning.

Chart 85: Teeth that Need Cleaning

Income Source	No	Yes	
Social Security	67	132	
	(33.7%)	(66.3%)	100%
Disability	5	17	
	(22.7%)	(77.3%)	100%
Work/Pay	19	15	
	(55.9%)	(44.1%)	100%
Combination of the 3	13	24	
	(35.1%)	(64.9%)	100%

Chi-square (3) = 8.02, p = .05

Relative to other groups, participants who receive disability had a higher percentage of participants reporting that their teeth needed to be cleaned. It should be noted that chi-squares with greater than 2 categories per variable pose a challenge in interpretation. The overall significant chi-square does not identify where specific differences lie between groups. Throughout this segment of the report, suggestions are provided for what appears to drive the significant result.

Chart 86 shows the means and standards deviations for responses to the question regarding grinding, soft, or fall-out teeth. Relative to other groups, participants who receive Disability reported a higher percentage of grinding, soft or falling out teeth.

Chart 86: Grinding, soft, or falling-out teeth

	No	Yes	
Social Security	154	45	
	(77.4%)	(22.6%)	100%
Disability	12	10	
	(54.5%)	(45.5%)	100%
Work/Pay	28	6	
	(82.4%)	(17.6%)	100%
Combination of the 3	32	5	
	(86.5%)	(13.5%)	100%

Chi-square (3) = 8.79, p = .03

As shown in Chart 87, relative to other groups, participants who receive Social Security had a higher percentage of participants indicate bad breath during the past 6 months.

Chart 87: Reported Bad Breath

	No	Yes
Social Security	88	82
	(51.8%)	(48.2%)
Disability	13	8
	(61.9%)	(38.1%)
Work/Pay	21	5
	(80.8%)	(19.2%)
Combination of the 3	24	12
	(57.7%)	(42.3%)
	100%	100%

Chi-square(3) = 9.46, p = .02

According to Chart 88, relative to other groups, participants who work had a lower percentage of participants indicate they have difficulty sitting still for a long time.

Chart 88: Reported Difficulty Sitting Still for a Long Time

	No	Yes	
Social Security	166	112	
	59.7%	40.3%	100%
Disability	16	11	
	59.3%	40.7%	100%
Work/Pay	46	3	
	93.9%	6.1%	100%
Combination of the 3	37	18	
	64.8%	35.2%	100%

Chi-square (3) = 21.83, p < .001

Relative to other groups, participants who work had a lower percentage of participants indicating that they have difficulty keeping their mouths open for a long time.

Chart 89: Reported Difficulty Keeping Mouth Open for a Long Time

	No	Yes	
Social Security	129	149	
	46.4%	53.6%	100%
Disability	12	15	
	44.4%	55.6%	100%
Work/Pay	44	5	
	89.8%	10.2%	100%
Combination of the 3	32	23	
	53.1%	46.9%	100%

Chi-square(3) = 32.88, p < .001

As shown in Chart 90, relative to other groups, participants who work had a lower percentage of participants indicate they have difficulty with the equipment that holds their mouths open.

Chart 90: Reported Difficulty with Equipment that Holds Open the Mouth

	No	Yes	
Social Security	163	115	
	58.6%	41.4%	100%
Disability	17	10	
	63%	37%	100%
Work/Pay	46	3	
	93.9%	6.1%	100%
Combination of the 3	38	17	
	69.1%	30.9%	100%

Chi-square(3) = 23.20, p < .001

As shown in Chart 91, relative to other groups, participants who work had a lower percentage of participants indicate they have difficulty with certain noises.

Chart 91: Reported Difficulty with Certain Noises

	No	Yes	
Social Security	201	77	
	72.3%	27.7%	100%
Disability	21	6	
	77.8%	22.2%	100%
Work/Pay	46	3	
	93.9%	6.1%	100%
Combination of the 3	41	14	
	75.6%	24.4%	100%
	100%	100%	100%

Chi-square (3) = 10.60, p = .01

Relative to other groups, participants who work had a larger percentage of participants indicate they have heart disease. These results should be interpreted with caution, since some cells have 0 cases.

Chart 92: Reported Heart Disease

	No	Yes
Social Security	265	13
	95.3%	4.7%
Disability	27	0
	100%	0%
Work/Pay	43	6
	87.8%	12.2%
Combination of the 3	55	0
	100%	0%
	100%	100%

Chi-square(3) = 10.38, p = .02

As indicated in Chart 93, relative to other groups, participants who receive disability had a larger percentage of participants indicate they have a history of contractures. These results should be interpreted with caution, since some cells have 0 cases.

Chart 93: Reported History of Contractures

	No	Yes
Social Security	251	27
	90.3%	9.7%
Disability	23	4
	85.2%	14.8%
Work/Pay	49	0
	100%	0%
Combination of the 3	53	2
	96.4%	3.6%
	100%	100%

Chi-square (3) = 8.43, p = .04

Charts 94 and 95 address the care of teeth. An analysis of variance was conducted to examine the difference in the overall rating of ability to care for teeth between the 4 different sources of income. There was a significant difference among the 4 means (F(3, 377) = 21.74, p < .001). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly greater independence (lower ratings) when caring of teeth (M = 1.15, sd = .61) than those who received Social Security (M = 2.73, sd = 1.17), Disability (M = 2.62, sd = 1.2), and the group that had some combination of the 3 (M = 2.19, sd = 1.1). Additionally, those in the "combination" group reported significantly greater independence (lower rating) than those who received Social Security.

Chart 94: Reported Ability to Care for Own Teeth

Income Source	n	Mean	Std. Deviation
Social Security	264	2.73	1.17
Disability	26	2.62	1.20/
Work/pay	34	1.15	.61
Combination of 3	54	2.19	1.10
Total	378	2.50	1.21

(1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me)

Chart 95: Analysis of Variance – Rating of Self-Care of Teeth by Source of Income

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	82.025	3	27.342	21.735	.000
Within Groups	470.472	374	1.258		
Total	552.497	377			

Charts 96 and 97 address frequency of flossing. An analysis of variance was conducted to examine the difference of the amount of flossing among the 4 different sources of income. As shown in Chart 97, there was a significant difference among the 4 means (F(3, 374) = 3.95, p < .01). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported flossing significantly more (M = 2.68, sd = 1.39) than those who received Social Security (M = 1.97, sd = 1.41) or Disability (M = 1.5, sd = .99).

Chart 96: Frequency of Flossing by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	260	1.97	1.41
Disability	26	1.50	.99
Work/pay	34	2.68	1.39
Combination of 3	55	2.07	1.39
Total	375	2.02	1.40

(1 = never, 7 = more than 3 times per day).

Chart 97: Analysis of Variance – Frequency of Flossing by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	22.500	3	7.500	3.945	.009
Within Groups	705.404	371	1.901		
Total	727.904	374			

Charts 98 and 99 pertain to reported dental problems. An analysis of variance was conducted to examine the difference of total number of dental problems reported between the 4 different sources of income. As indicated in Chart 99, there was a significant difference among the 4 means (F(3, 408) = 3.70, p = .01). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly fewer dental problems (M = 1.35, sd = 1.77) than those who received Disability (M = 2.8, sd = 2.4).

Chart 98: Total Number of Reported Dental Problems by Income Source

Income source	n	Mean	Std. Deviation
Social Security	278	1.90	1.81
Disability	27	2.81	2.35
Work/pay	49	1.35	1.77
Combination of 3	55	1.80	1.82
Total	409	1.88	1.87

Chart 99: Analysis of Variance – Total Number of Reported Dental Problems by Income Source

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	37.937	3	12.646	3.695	.012
Within Groups	1385.951	405	3.422		
Total	1423.888	408			

Charts 100 and 101 pertain to the total number of dental problems reported over the recent 6-month period. An analysis of variance was conducted to examine the difference of total number of dental problems over the past 6 months between the 4 different sources of income. As shown in Chart 101, there was a significant difference among the 4 means (F(3, 408) = 2.78, p = .04). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly fewer dental problems over past 6 months (M = 1.74, sd = .94) than those who received Disability (M = 2.22, sd = 2.44).

Chart 100: Total Number of Dental Problems over the Past Six Months by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	278	1.50	1.884
Disability	27	2.22	2.44
Work/pay	49	.94	1.74
Combination of 3	55	1.49	1.63
Total	409	1.48	1.89

Chart 101: Analysis of Variance – Total Number of Dental Problems over the Past Six Months by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	29.345	3	9.782	2.777	.041
Within Groups	1426.728	405	3.523		
Total	1456.073	408			

Charts 102 and 103 pertain to the total reported number difficulties in the dentist chair by income source. An analysis of variance was conducted to examine the difference in total number of difficulties in the dentist chair between the 4 different sources of income. As shown in Chart 103, there was a significant difference among the 4 means ($F(3, 408) = 9.65$, $p < .001$). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly fewer difficulties in the dentist chair ($M = .55$, $sd = 1.10$) than those who received Social Security ($M = 2.12$, $sd = 2.05$), Disability ($M = 2.15$, $sd = 2.07$), and the group that had some combination of the 3 ($M = 1.65$, $sd = 1.79$).

Chart 102: Total Reported Number of Difficulties in the Dentist Chair by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	278	2.12	2.05
Disability	27	2.15	2.07
Work/pay	49	.55	1.10
Combination of 3	55	1.65	1.79
Total	409	1.87	1.99

Chart 103: Analysis of Variance – Total Number of Difficulties in the Dentist Chair by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	107.581	3	35.860	9.645	.000
Within Groups	1505.808	405	3.718		
Total	1613.389	408			

Charts 104 and 105 pertain to the total number of dental tools used according to income source. An analysis of variance was conducted to examine the difference in total number of dental tools used between the 4 different sources of income. As shown in Chart 105, there was a significant difference among the 4 means ($F(3, 408) = 3.69$, $p = .01$). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported using significantly fewer dental tools ($M = .86$, $sd = .68$) than those who received Social Security ($M = 1.19$, $sd = .71$).

Chart 104: Total Number of Dental Tools Used by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	278	1.19	.71
Disability	27	1.07	.47
Work/pay	49	.86	.68
Combination of 3	55	1.16	.46
Total	409	1.14	.67

Chart 105: Analysis of Variance – Total Number of Dental Tools Used by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	4.885	3	1.628	3.687	.012
Within Groups	178.890	405	.442		
Total	183.775	408			

Chart 106 indicates that relative to other groups, participants who receive Disability Benefits had a larger percentage of participants indicate they went to the dentist for a regular check-up the last time they visited the dentist. This interpretation must be made with caution, based upon one cell's having "0" as the response.

Chart 106: Reported Reason for Most Recent Visit to Dentist as Regular Check-Up by Income Source

	No	Yes	
Social Security	124	146	
	45.9%	54.1%	100%
Disability	23	4	
	32%	68%	100%
Work/Pay	49	0	
	61.2%	38.8%	100%
Combination of the 3	53	2	
	38.5%	61.5%	100%

Chi-square (3) = 7.74, p = .05

As shown on Chart 107, relative to other groups, participants with some combination of types of income had a higher percentage of participants who indicate that they went to the dentist the last time to have their teeth cleaned.

Chart 107: Reported Reason for Most Recent Visit to Dentist as Teeth Cleaning by Income Source

	No	Yes	
Social Security	108	162	
	40%	60%	100%
Disability	12	13	
	48%	52%	100%
Work/Pay	31	18	
	63.3%	36.7%	100%
Combination of the 3	14	38	
	26.9%	73.1%	100%

Chi-square(3) = 14.78, p < .01

Chart 108 shows the means and standard deviations for the four different income groups.

Chart 108: Total Reasons for Most Recent Visit to Dentist by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	278	1.67	1.04
Disability	27	1.63	1.08
Work/pay	49	1.22	1.09
Combination of 3	55	1.87	1.04
Total	409	1.64	1.06

An analysis of variance was conducted to examine the difference in total number of reasons for the last visit to the dentist between the 4 different sources of income. There was a significant difference among the 4 means (F(3, 408) = 3.55, p = .02). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly fewer reasons for the last visit to the dentist (M = 1.22, sd = 1.09) than those who received Social Security (M = 1.67, sd = 1.04), and the group that had some combination of the 3 (M = 1.87, sd = 1.06).

Chart 109: Analysis of Variance – Total Reasons for Most Recent Visit to Dentist by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	11.734	3	3.911	3.551	.015
Within Groups	446.148	405	1.102		
Total	457.883	408			

As shown on Chart 110, Relative to other groups, participants who receive disability had a higher percentage of participants who indicated that being on a wait list for dental care has stopped them from going to the dentist.

Chart 110: Reason for Not Going to Dentist – on Waiting List, by Income Source

	No	Yes	
Social Security	271	7	
	97.5%	2.5%	100%
Disability	23	4	
	85.2%	14.8%	100%
Work/Pay	46	3	
	93.9%	6.1%	100%
Combination of the 3	53	2	
	96.4%	3.6%	100%

Chi-square (3) = 10.62, p = .01

Chart 111 summarizes the obstacle of insurance plan's not paying for dental care, by income source. Relative to other groups, participants who work had a lower percentage of participants indicating as their reason for not going to the dentist that their insurance plan does not pay for dental care.

Chart 111: Reason for Not Going to Dentist – Insurance Plan does not Pay for Dental Care, by Income Source

	No	Yes	
Social Security	182	96	
	65.5%	34.5%	100%
Disability	18	9	
	66.7%	33.3%	100%
Work/Pay	45	4	
	91.8%	8.2%	100%
Combination of the 3	39	16	
	70.9%	29.1%	100%

Chi-square (3) = 13.80, p = .003

As shown in Chart 112, relative to other groups, participants who receive Disability had a lower percentage of participants who indicated that their most recent visit to the dentist/hygienist the last time was to receive regular preventive care.

Chart 112: Reason for Going to Dentist/Hygienist for Regular Preventive Care – by Income Source

	No	Yes	
Social Security	169	109	
	60.8%	39.2%	100%
Disability	23	4	
	85.2%	14.8%	100%
Work/Pay	37	12	
	75.5%	24.5%	100%
Combination of the 3	39	16	
	70.9%	29.1%	100%

Chi-square(3) = 10.25, p = .02

Chart 113 shows the total number of reasons for most recent dentist/dental hygienist visit, according to source of income.

Chart 113: Total Number of Reasons for Most Recent Dentist/Hygienist Visit, by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	278	1.33	1.05
Disability	27	1.04	1.09
Work/pay	49	.90	.80
Combination of 3	55	1.18	1.06
Total	409	1.24	1.04

An analysis of variance was conducted to examine the difference in total number of reasons for the last visit to the dentist/ dental hygienist between the 4 different sources of income. There was a significant difference among the 4 means (F(3, 408) = 2.94, p = .03). Post-hoc tests revealed that participants who reported work/pay as the sole income source reported significantly fewer reasons for the last visit to the dentist/dental hygienist (M = .90, sd = .80) than those who received Social Security (M = 1.33, sd = 1.05).

Chart 114: Analysis of Variance – Total Number of Reasons for Most Recent Dental Visit, by Source of Income

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	9.330	3	3.110	2.935	.033
Within Groups	429.189	405	1.060		
Total	438.518	408			

Chart 115 shows the means of the last time the participant had teeth cleaned by a dentist or dental hygienist. (1 = within the past year, 4 = more than 5 years ago)

Chart 115: Timing of Most Recent Teeth Cleaning by Income Source

Income Source	n	Mean	Std. Deviation
Social Security	255	1.74	1.00
Disability	23	2.30	1.36
Work/pay	35	1.89	1.11
Combination of 3	50	1.58	.93
Total	363	1.77	1.04

An analysis of variance was conducted to examine the difference in time of the last teeth cleaning by a dentist/ dental hygienist between the 4 different sources of income. There was a significant difference among the 4 means ($F(3, 362) = 2.87$, $p = .04$). Post-hoc tests revealed that participants who indicated disability reported a significantly longer time since their last teeth cleaning by a dentist/dental hygienist ($M = 2.30$, $sd = 1.36$) than those who reported some combination of the three ($M = 1.58$, $sd = .93$).

Chart 116: Analysis of Variance – Timing of Most Recent Teeth Cleaning by Income Source

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	9.108	3	3.036	2.868	.036
Within Groups	379.989	359	1.058		
Total	389.096	362			

Dental Insurance

Significant differences by dental insurance on dental health items. Here, only significant chi-squares and ANOVAs are reported. Tukey's HSD post-hoc tests were conducted for significant ANOVAs. As a result of unequal proportions of participants with types of dental insurance (most participants do not have dental insurance), the percentages in the chi-square table are shown across to reflect the within-group breakdown.

Chart 116: Description of Mouth and Teeth Condition by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/ Medicaid/AHCCCS)	127	2.33	.98
Private	84	2.77	.87
None	178	2.14	1.01
Total	389	2.34	1.00

(poor = 1, very good = 4) (Note: Does not include "don't know")

An analysis of variance was conducted to examine the difference of the overall rating of condition of teeth among the three dental insurance groups. There was a significant difference among the three means ($F(2, 388) = 12.14$, $p < .001$). Post-hoc tests revealed that participants with private dental insurance reported significantly higher ratings of the condition of their teeth ($M = 2.77$, $sd = .87$) than those who had public ($M = 2.33$, $sd = .98$) or no insurance ($M = 2.14$, $sd = 1.0$).

Chart 117: Analysis of Variance – Condition of Teeth by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	22.907	2	11.453	12.136	.000
Within Groups	364.301	386	.944		
Total	387.208	388			

Chart 118: Description of Gums Condition by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/ Medicaid/AHCCCS)	124	2.40	.97
Private	83	2.80	.85
None	178	2.18	1.01
Total	385	2.38	.99

(poor = 1, very good = 4)

As shown in Chart 119, an analysis of variance was conducted to examine the difference of the overall rating of condition of gums among the 3 dental insurance groups. There was a significant difference among the 3 means ($F(2, 384) = 11.54$, $p < .001$). Post-hoc tests revealed that participants with private dental insurance reported significantly higher ratings of the condition of their gums ($M = 2.80$, $sd = .85$) than those who had public ($M = 2.40$, $sd = .97$) or no insurance ($M = 2.18$, $sd = 1.01$).

Chart 119: Analysis of Variance – Description of Gums by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	21.470	2	10.735	11.539	.000
Within Groups	355.402	382	.930		
Total	376.873	384			

As noted in Chart 120, relative to other groups, those with private insurance had a lower percentage of participants who reported having cavities.

Chart 120: Reported Problems with Teeth – Cavities by Insurance Type

Dental Insurance	No	Yes	
Public (Medicare/Medicaid/AHCCCS)	54	36	
	(60%)	(40%)	100%
Private	51	18	
	(73.9%)	(26.1%)	100%
None	69	66	
	(51.1%)	(48.9%)	100%

Chi-square(2) = 9.86, p = .01

As shown in Chart 121, relative to other groups, those with private insurance had a lower percentage of participants with broken or missing teeth.

Chart 121: Reported Problems with Teeth – Broken or Missing Teeth that Impair My Ability to Eat, by Insurance Type

Dental Insurance	No	Yes	
Public	71	19	
(Medicare/Medicaid/AHCCCS)	(78.9%)	(21.1%)	100%
Private	64	5	
	(92.8%)	(7.2%)	100%
None	100	35	
	(74.1%)	(25.9%)	100%

Chi-square(2) = 10.02, p = .01

As presented in Chart 122, relative to other groups, those with no insurance had a higher percentage of participants with teeth that need cleaning.

Chart 122: Reported Problems with Teeth – Teeth that Need Cleaning, by Insurance Type

Dental Insurance	No	Yes	
Public	34	56	
(Medicare/Medicaid/AHCCCS)	(37.8%)	(62.2%)	100%
Private	38	31	
	(55.1%)	(44.9%)	100%
None	33	102	
	(24.4%)	(75.6%)	100%

Chi-square(2) = 18.90, p < .001

As noted in Chart 123, relative to other groups, those with no insurance had a higher percentage of participants with gum problems.

Chart 123: Reported Problems with Teeth – Gum Problems, by Insurance Type

Dental Insurance	No	Yes	
Public	53	37	
(Medicare/Medicaid/AHCCCS)	(58.9%)	(41.1%)	100%
Private	48	21	
	(69.6%)	(30.4%)	100%
None	59	76	
	(43.7%)	(56.3%)	100%

Chi-square(2) = 13.36, p = .001

Relative to other groups, those with private insurance had a lower percentage of participants with bad breath.

Chart 124: Reported Problem Lasting More than a Day in Past Six Months – Bad Breath, by Insurance Type

Dental Insurance	No	Yes	
Public	33	40	
(Medicare/Medicaid/AHCCCS)	(45.2%)	(54.8%)	100%
Private	43	9	
	(82.7%)	(17.3%)	100%
None	71	59	
	(54.6%)	(45.4%)	100%

Chi-square(2) = 18.48, p < .001

As indicated in Chart 125, relative to other groups, those with no insurance had a higher percentage of participants with problems with teeth and/or gums that makes it painful to eat.

Chart 125: Reported Problem with Teeth and/or Gums Making Eating Painful, by Insurance Type

Dental Insurance	No	Yes	
Public	99	22	
(Medicare/Medicaid/AHCCCS)	(81.8%)	(18.2%)	100%
Private	74	9	
	(89.2%)	(10.8%)	100%
None	132	44	
	(75%)	(25%)	100%

Chi-square(2) = 7.41, p = .03

Relative to other groups, those with private insurance had a lower percentage of participants with difficulty sitting still for a long time.

Chart 126 Reported Difficulty Sitting Still for a Long Time, by Insurance Type

Dental Insurance	No	Yes	
Public	81	52	
(Medicare/Medicaid/AHCCCS)	(60.9%)	(39.1%)	100%
Private	71	20	
	(78%)	(2%)	100%
None	113	76	
	(59.8%)	(40.2%)	100%

Chi-square(2) = 9.79, p = .01

As shown on Chart 127, relative to other groups, those with public dental insurance had a higher percentage of participants with difficulty with equipment that holds open the mouth.

Chart 127: Reported Difficulty with Equipment that Holds Open the Mouth, by Insurance Type

Dental Insurance	No	Yes	
Public (Medicare/Medicaid/AHCCCS)	75	58	
	(56.4%)	(43.6%)	100%
Private	68	23	
	(74.7%)	(25.3%)	100%
None	120	69	
	(63.5%)	(36.5%)	100%

Chi-square(2) = 7.86, p = .02

Chart 128 indicates the total reported number of difficulties in the dentist chair, by insurance type.

Chart 128: Total Number of Difficulties in Dentist Chair Reported, by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	133	2.11	1.97
Private (from a private carrier)	91	1.40	1.81
None	189	2.02	2.08
Total	413	1.91	2.00

An analysis of variance was conducted to examine the difference in total number of difficulties in the dentist chair among the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 412) = 3.98, p = .02). Post-hoc tests revealed that participants with private dental insurance reported significantly fewer difficulties (M = 1.40, sd = 1.81) than those who had public insurance (M = 2.11, sd = 1.97) or no insurance (M = 2.02 , sd = 2.08).

Chart 129: Analysis of Variance – Difference in Total Number of Difficulties in Dentist Chair, by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	31.485	2	15.743	3.979	.019
Within Groups	1622.200	410	3.957		
Total	1653.685	412			

As shown on Chart 130, participants reported on their individual ability to care for their own teeth, by Insurance type.

Chart 130: Reported Ability to Care for Own Teeth, by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	126	2.47	1.17
Private	79	1.99	1.21
None	180	2.78	1.17
Total	385	2.51	1.21

(1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me)

An analysis of variance was conducted to examine the difference of ability to care for teeth independently among the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 384) = 12.47, p < .001).

Post-hoc tests revealed that participants with private dental insurance reported significantly greater independence (lower means) (M = 1.99, sd = 1.21) than those who had public (M = 2.47, sd = 1.17) or no insurance (M = 2.78, sd = 1.17).

Chart 131: Analysis of Variance – Ability to Care for Own Teeth, by Insurance Group

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	34.700	2	17.350	12.470	.000
Within Groups	531.471	382	1.391		
Total	566.171	384			

As shown in Chart 132, participants reported their total number of dental problems.

Chart 132: Total Number of Dental Problems by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/ Medicaid/AHCCCS)	133	1.67	1.71
Private	91	1.43	1.46
None	189	2.25	2.06
Total	413	1.88	1.86

An analysis of variance was conducted to examine the difference in total number of dental problems among the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 412) = 7.57, p < .001). Post-hoc tests revealed that participants with no dental insurance reported significantly more dental problems (M = 2.25, sd = 2.06) than those who had private (M = 1.43, sd = 1.46) or public insurance (M = 1.67, sd = 1.71).

Chart 133: Analysis of Variance – Total Number of Dental Problems by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	50.882	2	25.441	7.572	.001
Within Groups	1377.539	410	3.360		
Total	1428.421	412			

As shown in Chart 134, participants reported the total number of dental problems faced over the past 6 months.

Chart: 134: Total Number of Dental Problems over the Past Six Months, by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	133	1.29	1.85
Private	91	1.00	1.53
None	189	1.84	1.99
Total	413	1.48	1.88

An analysis of variance was conducted to examine the difference in total number of dental problems reported in the last 6 months among the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 412) = 7.30, p < .001). Post-hoc tests revealed that participants with no dental insurance reported significantly more dental problems in the last 6 months (M = 1.84, sd = 2.00) than those who had private (M = 1.00, sd = 1.53) or public insurance (M = 1.29, sd = 1.85).

Chart 135: Analysis of Variance – Total Number of Dental Problems over the Past Six Months, by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	50.273	2	25.137	7.295	.001
Within Groups	1412.802	410	3.446		
Total	1463.075	412			

Chart 136 summarizes respondents reported timing of my recent dental visit, by type of insurance.

Chart 136: Reported Timing of Most Recent Dental Visit

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	127	1.61	1.02
Private	80	1.50	.95
None	181	1.86	1.06
Total	388	1.70	1.03

(1 = within the past year, 4 = more than 5 years ago)

An analysis of variance was conducted to examine the difference in length of time since last dentist visit among the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 387) = 4.32, p = .01). Post-hoc tests revealed that participants with no dental insurance reported significantly longer time since last dentist visit (M = 1.86, sd = 1.06) than those who had private insurance (M = 1.50, sd = .95).

Chart 137: Analysis of Variance – Reported Timing of Most Recent Dental Visit, by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	9.053	2	4.527	4.315	.014
Within Groups	403.862	385	1.049		
Total	412.915	387			

In Chart 138, responses of participants who reported their reason for the most recent dental visit as bleeding gums, are summarized. Relative to other groups, those with no insurance had a higher percentage of participants who reported seeing the dentist last time for bleeding gums.

Chart 138: Reported Reason for Most Recent Dental Visit – Bleeding gums, by Insurance Type

Dental Insurance	No	Yes	
Public (Medicare/Medicaid/AHCCCS)	122	8	
	(93.8%)	(6.2%)	100%
Private	88	2	
	(97.8%)	(2.2%)	100%
None	157	21	
	(88.2%)	(11.8%)	100%

Chi-square(2) = 8.35, p = .02

Chart 139 summarizes reported reason for not going to the dentist as “No money to pay for dental care.” Relative to other groups, those with no insurance had a higher percentage of participants who reported no money to pay for dental care as a reason for not going to the dentist.

Chart 139: Reported Reason for Not Going to Dentist – No Money to Pay for Dental Care, by Insurance Type

Dental Insurance	No	Yes	
Public	100	33	
(Medicare/Medicaid/AHCCCS)	(75.2%)	(24.8%)	100%
Private	71	20	
	(78%)	(22%)	100%
None	91	98	
	(48.1%)	(51.9%)	100%

Chi-square(2) = 35.31, p < .001

Chart 140 summarizes responses to the question “Total number of reasons for not going to the dentist”, as reported by insurance type.

Chart 140: Total Number of Reasons for Not Going to the Dentist, by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	133	.7669	1.01420
Private (from a private carrier)	91	.5714	1.07644
None	189	1.2116	1.14746
Total	413	.9274	1.12109

An analysis of variance was conducted to examine the difference in total number of reasons for not going to the dentist between the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 412) = 12.71, p < .001). Post-hoc tests revealed that participants with no dental insurance reported significantly more reasons for not going to the dentist (M = 1.21, sd = 1.15) than those who had private (M = .57, sd = 1.08) or public insurance (M = .77, sd = 1.01).

Chart 141: Analysis of Variance – Total Number of Reasons for Not Going to the Dentist, by Insurance Type

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	30.226	2	15.113	12.708	.000
Within Groups	487.595	410	1.189		
Total	517.821	412			

Chart 142 summarizes responses to the question when the most recent professional teeth cleaning took place.

Chart 142: Most Recent Time of Teeth Cleaning by Dental Professional, by Insurance Type

Dental Insurance	n	Mean	Std. Deviation
Public (Medicare/Medicaid/AHCCCS)	115	1.66	1.02
Private	80	1.56	.94
None	173	1.97	1.07
Total	368	1.78	1.04

(1 = within the past year, 4 = more than 5 years ago)

An analysis of variance was conducted to examine the difference of the length of time since the last teeth cleaning between the 3 dental insurance groups. There was a significant difference among the 3 means (F(2, 367) = 5.38, p < .01). Post-hoc tests revealed that participants with no dental insurance reported significantly longer time since their last teeth cleaning (M = 1.97, sd = 1.07) than those who had private (M = 1.56, sd = .94) or public insurance (M = 1.66, sd = 1.01).

Chart 143: Analysis of Variance – Timing of Most Recent Professional Teeth Cleaning, by Insurance Group

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	11.355	2	5.678	5.379	.005
Within Groups	385.253	365	1.055		
Total	396.609	367			

Chart 144 summarizes reported stained, yellow, or blackened teeth as a reason for the most recent visit to the dentist, by insurance type. Relative to other groups, those with private insurance had a lower percentage of participants who reported stained, yellow, or blackened teeth as a reason for their last visit to the dentist/hygienist.

Chart 144: Reason for Most Recent Visit to Dentist as Stained, Yellowed, or Blackened Teeth, by Insurance Type

Dental Insurance	No	Yes	
Public (Medicare/Medicaid/AHCCCS)	121	12	
	(91%)	(9%)	100%
Private	90	1	
	(98.9%)	(1.1%)	100%
None	173	16	
	(91.5%)	(8.5%)	100%

Chi-square(2) = 6.31, p = .04

Independence in Care of Teeth

Chart 145 shows the correlations (Spearman's rank correlation) of individual items and item Q27, which assesses the level of independence of caring for one's teeth. Unless otherwise noted, No = 0 and Yes = 1. Q27 is coded: 1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me. A positive correlation means that those that are more *dependent* are more likely to respond "Yes," than those who are more *independent*. A negative correlation means that those who are more *independent* are more likely to respond "Yes," than those that are more *dependent*.

As shown in Chart 145, independence in care of teeth was associated with multiple features that pertained to rating of conditions of teeth and gums, while less independent performance was associated the reported problems, such as eating, difficulty having equipment in mouth, and a variety of dental challenges.

Chart 145: Correlation between Independence in Care of Teeth and Dental Factors

Question	Spearman's rank correlation	Interpretation
Q20: I would describe the condition of my mouth and teeth as: (poor = 1 very good = 4)	r = -.21, p < .001	Greater independence in dental care is associated with higher ratings of condition of teeth
Q21: I would describe the condition of my gums as: (poor = 1 very good = 4)	r = -.24, p < .05	Greater independence in dental care is associated with higher ratings of condition of gums
Q22-5: Teeth that need cleaning	r = .25, p < .05	Those with less independence in dental care reported needing teeth cleaning more than those with greater independence
Q22-6: Gum problems	r = .14, p = .02	Those with less independence in dental care reported gum problems more often than those with greater independence
Q22-7: Grinding, soft or falling out teeth	r = .17, p < .01	Those with less independence in dental care reported grinding, soft or falling out teeth more often than those with greater independence
# of dental problems	r = .14, p < .01	Less independence in dental care was associated with greater total number of dental problems
Q23-1: Past 6 months: Difficulty eating or chewing	r = .16 p =.01	Those with less independence in dental care reported difficulty eating or chewing over past 6 months more often than those with greater independence
Q23-6: Past 6 months: Sores in mouth	r = .14, p = .03	Those with less independence in dental care reported sores in mouth over past 6 months more often than those with greater independence
Q23-10: Past 6 months: Broken or missing fillings	r = -.17, p < .01	Those with greater independence in dental care reported broken or missing fillings over past 6 months more often than those with less independence
Q23-12: Past 6 months: bad breath	r = .17 , p = .01	Those with less independence in dental care reported bad breath over past 6 months more often than those with greater independence
# of dental problems during last 6 months (sum of the number of problems during past 6 months each participant reported)	r = .18, p < .001	Less independence in dental care was associated with greater total number of dental problems over the past 6 months
Q24: I have a problem with my teeth and/ or gums that makes it painful to eat	r = .11, p = .04	Those with less independence in dental care reported having problems with teeth/gums that makes it painful to eat more often than those with greater independence
Q25-1: The following situations apply to me in the dentist chair: I have difficulty sitting still for a long time	r = .41, p < .001	Those with less independence in dental care reported having difficulty sitting still for a long time more often than those with greater independence
Q25-2: The following situations apply to me in the dentist chair: I have difficulty keeping my mouth open for a long time	r = .38, p < .001	Those with less independence in dental care reported having difficulty keeping their mouths open for a long time more often than those with greater independence

Q25-3: The following situations apply to me in the dentist chair: I have difficulty with equipment that holds my mouth open	r = .39, p < .001	Those with less independence in dental care reported having difficulty with the equipment that holds the mouth open more often than those with greater independence
Q25-4: The following situations apply to me in the dentist chair: I have difficulty with florescent lighting	r = .14, p < .01	Those with less independence in dental care reported having difficulty with florescent lighting more often than those with greater independence
Q25-5: The following situations apply to me in the dentist chair: I have difficulty with certain noises	r =.24, p < .001	Those with less independence in dental care reported having difficulty with certain noises more often than those with greater independence
Q25-6: The following situations apply to me in the dentist chair: I am very afraid of dental work	r = .21, p < .001	Those with less independence in dental care reported having being very afraid of dental work more often than those with greater independence
# of Difficulties in dentist chair (Sum of number of difficulties reported per participant)	r = .42, p < .001	Less independence in dental care was associated with greater total number of difficulties in the dentist chair
Q26-1: Health conditions: Diabetes	r = -.10, p < .5	Those with greater independence in dental care reported having diabetes more often than those with less independence
Q26-5: Health conditions: History of contractures	r = .26, p < .001	Those with less independence in dental care reported having a history of contractures more often than those with greater independence
Q29: I floss my teeth (1 = never, 7 = more than 3 times per day)	r = -.12, p = .02	Greater independence in dental care was associated with more frequent teeth flossing
Q30-1: Dental tools: Regular toothbrush	r = -.15, p < .01	Those with greater independence in dental care reported using a regular toothbrush more often than those with less independence
Q30-3: Dental tools: Electric toothbrush	r = .15, p < .01	Those with less independence in dental care reported using an electric toothbrush more often than those with greater independence
Q33-9: My reason for visiting a dentist the last time was: Bleeding gums or periodontal disease	r = .13, p < .01	Those with less independence in dental care reported bleeding or periodontal disease as a reason for their last dentist visit more often than those with greater independence
Q34-5: The following have stopped me from going to the dentist: Insurance plan does not pay for dental care	r =.17, p < .001	Those with less independence in dental care reported that their insurance plan does not cover dental care as a reason for not going to the dentist more often than those with greater independence
# of reasons for not going to the dentist	r = .11, p = .04	Less independence in dental care was associated with greater total number of reasons for not going to the dentist
Q36-4: Reason for last visit to dentist/hygienist: Gum problems	r = .15, p < .01	Those with less independence in dental care reported gum problems as a reason for their last dentist/hygienist visit more often than those with greater independence

Q36-5: Reason for last visit to dentist/hygienist: Regular preventative care	r = .20, p < .001	Those with less independence in dental care reported regular preventive care as a reason for their last dentist/hygienist visit more often than those with greater independence
# of reasons for last dentist/hygienist visit: (Sum of number of reasons for going to the dentist/hygienist)	r = .11, p < .05	Less independence in dental care was associated with greater total number of reasons for their last visit to the dentist/hygienist
Q38-6: My reason for visiting the ER for dental issues the last time was: Sores in my mouth	r =.28, p = .05	Those with less independence in dental care reported sores in their mouths as a reason for their last dental-related ER visit more often than those with greater independence
Q38-10: My reason for visiting the ER for dental issues the last time was: Broken or missing fillings	r = -.29, p = .04	Those with greater independence in dental care reported broken or missing fillings as a reason for their last dental-related ER visit more often than those with less independence

1 = by myself very well, 2 = with difficulty by myself, 3 = with assistance 4 = caregiver must do this for me.

Total Number of Dental Problems

Chart 146 reports the correlations between total number of dental problems (sum of Q22) and number of teeth removed, condition of teeth and gums, frequency of teeth brushing, flossing, length of time since last dentist visit, and length of time since last teeth cleaning.

Chart 146: Correlations between Total Number of Dental Problems and Multiple Dental Factors

Question	Spearman's rank correlation	Interpretation
Q16: The number of my permanent teeth removed because of tooth decay or gum disease is: (0 = None, 1 = 1 to 5, 2 = 6 +, but not all, 3 = all)	r = .30, p < .001	Greater total number of dental problems was associated with greater number of teeth removed
Q17: I have all of my teeth:	r = -.26, p < .001	Those with fewer total dental problems were more likely to report having all of their teeth
Q18: I have no teeth:	r = -.21, p < .001	Those with fewer total dental problems were more likely to report having no teeth
Q20: I would describe the condition of my mouth and teeth as: (poor = 1, very good = 4)	r = -.66, p < .001	Greater total number of dental problems was associated with poorer mouth condition
Q21: I would describe the condition of my gums as: (poor = 1, very good = 4)	r = -.65, p < .001	Greater total number of dental problems was associated with poorer gum condition
Q28: I brush my teeth (1 = less than once per day, 5 = more than 3 times per day)	r = -.10, p < .05	Greater total number of dental problems was associated with less frequent teeth brushing
Q29: I floss my teeth (1 = never, 7 = more than 3 times per day)	r = -.15, p < .01	Greater total number of dental problems was associated with less frequent flossing

Q31: The last time I visited the dentist or dental clinic for any reason (including visits to dental specialists, such as orthodontists) was: (1 = within the past year, 2 = within the last 2 years, 3 = within the past 5 years, 4 = 5 or more years ago)	r = .21, p < .001	Greater total number of dental problems was associated with a greater length in time since last dentist visit
Q35: The last time I had my teeth cleaned by a dentist or dental hygienist was: (1 = within the past year, 2 = within the last 2 years, 3 = within the past 5 years, 4 = 5 or more years ago)	r = .30, p < .001	Greater total number of dental problems was associated with a greater length in time since last dental cleaning

Chart 147 reports the correlations between total number of dental problems in the last six months and the number of teeth removed, condition of teeth and gums, frequency of teeth brushing, flossing, length of time since last dentist visit, and length of time since last teeth cleaning.

Chart 147: Correlations between Total Number of Dental Problems in last 6 Months and Multiple Dental Factors

Question	Spearman's rank correlation	Interpretation
Q16: The number of my permanent teeth removed because of tooth decay or gum disease is: (0 = None, 1 = 1 to 5, 2 = 6 +, but not all, 3 = all)	r = .36, p < .001	Greater total number of dental problems over past 6 months was associated with greater number of teeth removed
Q17: I have all of my teeth:	r = -.25, p < .001	Those with fewer total dental problems over past 6 months were more likely to report having all of their teeth
Q20:I would describe the condition of my mouth and teeth as: (poor = 1, very good = 4)	r = -.57, p < .001	Greater total number of dental problems over past 6 months was associated with poorer mouth condition
Q21:I would describe the condition of my gums as: (poor = 1, very good = 4)	r = -.61, p < .001	Greater total number of dental problems over past 6 months was associated with poorer gum condition
Q28: I brush my teeth (1 = less than once per day, 5 = more than 3 times per day)	r = -.12, p < .05	Greater total number of dental problems over past 6 months was associated with less frequent teeth brushing
Q29: I floss my teeth (1 = never, 7 = more than 3 times per day)	r = -.10, p < .05	Greater total number of dental problems over past 6 months was associated with less frequent flossing
Q31: The last time I visited the dentist or dental clinic for any reason (including visits to dental specialists, such as orthodontists) was: (1 = within the past year, 2 = within the last 2 years, 3 = within the past 5 years, 4 = 5 or more years ago)	r = .20, p < .001	Greater total number of dental problems over past 6 months was associated with a greater length in time since last dentist visit
Q35: The last time I had my teeth cleaned by a dentist or dental hygienist was: (1 = within the past year, 2 = within the last 2 years, 3 = within the past 5 years, 4 = 5 or more years ago)	r = .27, p < .001	Greater total number of dental problems over past 6 months was associated with a greater length in time since last dental cleaning

Qualitative Input and Personal Narratives: "Information I Want to Share About My Dental Care Needs"

Participants in the primary consumer survey were asked a final, open-ended question about their dental care needs. Responses represent unprompted indications of areas that concern consumers. Open-ended responses totaled 180 of 466 total responses received, representing 38.62% of total respondents. Responses were classified by emergent topic, rather than pre-determined. That is, each of the qualitative responses was read and placed in the primary topic category that emerged from the language used. In many instances, comments could be classified into more than one category. For purposes of clarity, a primary category was established for each. Comments were thereby placed into those categories. As shown in Chart 148, categories are listed in order of frequency, with the two highest categories "Lack of Funding" (41 separate comments, representing 23% of total comments, and "Need for Sedation/Anesthesia," representing 35 separate comments, equaling 19% of total comments).

Chart 148: Summary Responses to Open-Ended Question: "Other Information about Dental Care Needs

Category	Number	Percentage
Lack of Funding	41	23%
Need for Sedation/Anesthesia	35	19%
Specified Treatment Needs	20	11%
Family Coverage or Private Pay	17	9%
Special Needs Dentistry	17	9%
Obstacles to Care	16	9%
Frequency of Cleaning	13	7%
Relationship to General Health	12	7%
Medication Issues	9	5%
Total	180	100%

For purposes of emphasis selected comments deemed by the researcher to be most illustrative of the issues under study were selected for inclusion in this report. A complete listing of the comments as classified according to Chart 69 appears in Appendix D.

Lack of Funding

Many respondents cited profound concerns about lack of funding. Both the factual and the emotional content of comments suggest the absence of functional choice and in many instances a recognition of consequences pertaining to overall health of the client. The three comments below clarify the reality faced by many Arizona consumers with developmental disabilities. Comment 1 is instructive from three different perspectives: (1) the condition of Cerebral Palsy as experienced by this consumer involves a reflexive response (biting and grinding) that precludes normal procedures in dental care. (2) Necessary sedation is highly costly, and beyond the means of consumers. (3) The sacrifice needed by the consumer's parents, represented by parents' cashing in their IRA, is clearly beyond their means, and represents the last resort in responsibility for caring for a loved one.

> "Lack of Funding" Selected Comment 1 of 3
> Because of severe Cerebral Palsy, I need total care. Whenever anything is put in my mouth, I bite it. My teeth are worn down from grinding, which I cannot control. Since I need to be sedated when going to the dentist, it is very costly. (About $3000 to $4000 every time I go. My parents had to cash their IRA to pay for my dental care.

Comment 2, below, articulates the exact amounts of money available to the consumer on a monthly basis, $698, for which, after room and board fees, leaves only $84 per month for all other expenses. The client performs limited functions for pay (cleaning and repairs), and is highly unlikely to be able to produce the funds needed for costly dental care that adult consumers who do not have Developmental Disabilities need not face.

"Lack of Funding" Selected Comment 2 of 3
This client Social Security payment of $698 of which $614 is used for room and board, leaves only $84 a month for all other needs. Has no dental insurance or other coverage for dental care. As she can manage she does cleaning and minor repairs as she has no other source of money.

Comment 3 illustrates a related situation of oral healthcare. First, the adult consumer needs to have teeth pulled, which is not addressed further in the comment. Parents have worked to pay for the stated $14,000 estimated for extraction of teeth and denture manufacture. The potential for "placing her outside the home because of this need" calls into question parents' consideration of seeking further public assistance.

An additional question arises from this comment: "Why must the consumer have her teeth pulled and obtain dentures?" While not stated as such, many other respondents have claimed the need to have teeth pulled due to neglect of prevention and regular care. In some instances, this is due to inaccessibility of the mouth, based upon Developmental Disabilities (biting reflex, size of mouth, etc.) or funding restrictions precluding care, or medications that threaten dental health.

"Lack of Funding" Selected Comment 3 of 3
The high cost of dental care! My daughter needs to now have teeth pulled and a set of dentures. The cost estimate was over $14,000. We have not been able to care for her dental and have considered placing her outside the home because of this need. We worked for over 10 years trying to pay for dentures.

Sedation Required

The area of required sedation was voiced by a similarly high number of consumer respondents. The comments selected provide illustrative qualitative indications of the issues faced by consumers. Comment 1, below, reveals multiple issues: (1) Delay of care due to necessity of anesthesia, contributes to pre-existing condition of choking when trying to swallow. (2) Inadequacy of preventive care in group home has consequences in both oral and general health, as reported. (3) Potential for mitigating risk situation through incentive-based stimulus may offer potential benefits to consumers.

"Sedation Required" Selected Comment 1 of 3
Waiting on dental care because I cannot afford general anesthesia. Currently have problems with choking because of difficulty swallowing. Cannot chew food very well, because only have a few teeth left. Group home staff does not do an adequate job brushing client's teeth. I would love to be able to set up an incentive program for staff if consumers have a good check-up because they really don't care about consumers' teeth.

Comment 2, noted below, indicates the following concerns: (1) Sedation, while unaffordable, is necessary, due to the need for restraining the consumer to perform dental work. (2) The clinic currently being used is scheduled to close in December, 2011, leaving the consumer without a dental care home. (3) Reflexive grinding of teeth, due to the consumer's health condition, is causing increasing damage to the teeth and gum. (4) Increasing discomfort has been noted. (5) The need for anesthesia/sedation, combined with its expense, precludes the performance of necessary oral health procedures that the consumer requires for quality of life.

"Sedation Required" Selected Comment 2 of 3
I need sedation for dentist. Dentist I go to is 40 miles from my home, and I must be restrained. I cannot afford IV sedation for dental work. The dental clinic I attend is closing in December 2011. I don't know what I will do about a dentist then. I grind my teeth and very front teeth are worn down to the gum, and it's becoming more uncomfortable for me. I have one crown that has cost several hundred dollars, and I can't afford more.

Comment 3, specified below, suggestions several issues: (1) Capacity of the dental care provider organization appeared not to serve the needs of this individual with special needs. (2) A pattern of delay in care has reportedly resulted in "frustrating and uneasy" feelings, and may have contributed to further deterioration of dental health of the patient. (3) Congestive heart failure, noted as related to general anesthesia, represents a great source of fear to the consumer.

"Sedation Required" Selected Comment 3 of 3
Dental provider did not have a doctor available that could do the procedure of cleaning and checking teeth between 2008 and 2010. There was always a new dentist when we went and they didn't do anything except try to check the teeth without x-rays or thorough check. It was always "come back later." The new dentist had problems with the anesthesia. I had to go to ICU for congestive heart failure due to anesthesia. Please, isn't there something, some way safer than general anesthesia? Congestive heart failure due to anesthesia is a scary, scary situation. New dentists every time you go to a clinic is also very frustrating and uneasy.

Specified Treatment and Needs

The area of Specified Treatment includes a range of issues pertaining to the result of existing policies and procedures in effect in AHCCCS, with emphasis on consumer and family response to the situation. Comment #1 reveals the following concerns: (1) Delay of approval for needed services exacerbates issues of care. (2) Contingencies such as weight loss, in spite of a reported underweight situation for the consumer, indicate a scenario worthy of further analysis, notably if the practice described disqualifies individuals who should be receiving treatment, from being assisted as needed. (3) Personal feelings of consumers and their families can be understood by the language of frustration and anger demonstrated in this comment.

"Specified Treatment and Needs" Selected Comment 1 of 3
I refused dental care through AHCCCS because all they do is pull them. They wait until the dental problems are so bad, that they actually told me that I couldn't get braces on my teeth till I lost at least 20 pounds due to not being able to eat, being very underweight, I couldn't afford to lose any weight. I feel that their reasoning is that because we are disabled, it doesn't matter what we look like or being able to eat. So OUR dental needs are NOT important.

Comment #2 suggests the following concerns: (1) As a condition of the particular health, possibly both the diagnosis and the prescriptions given for symptoms of the individual respondent, both gums and teeth are deteriorating. (2) The loss of crowns and the loss of teeth represent real issues that need direct and immediate attention of a dental professional. (3) The stress of anticipating the lack of any coverage for dental needs as the individual client ages, comes through clearly, and warrants attention.

"Specified Treatment and Needs" Selected Comment 2 of 3
Due to my disability, my gums are deteriorating quickly, and the enamel on my teeth is almost completely gone. I have missing teeth and many silver crowns. I worry about what will happen to the rest of my teeth when my dental insurance goes away at age 22. My family cannot afford dental care.

Comment #3 provides an illustration of another real-life scenario experienced both by consumer and by his family caregiver: (1) The absence of dental visits for a period of 15 years would be extraordinary for an adult individual without Developmental Disabilities. (2) It is reasonable to assume that favorable factors not known based upon the comment may be, in part, responsible for the absence of cavities. (3) The saving of funds by a family member, committed to paying for all needed work, represents a substantial sacrifice. (4) The root canal, deep cleaning, and x-rays represent expensive treatment, for which the family took full responsibility, in the absence of any public funding.

"Specified Treatment and Needs" Selected Comment 3 of 3
Has not been to the dentist in over 15 years. I saved enough money to take him. He needed a root canal, deep cleaning of entire mouth, x-rays, but there weren't any cavities. I am his sister and caregiver, and he lives with me.

Family Dental Coverage or Private Pay

The area of Family Dental Coverage or Private Pay illustrates several aspects of insurance coverage that warrant attention as part of the exploration of the financial issues pertaining to the oral healthcare of adults with developmental disabilities. The first comment selected illustrates these concerns: (1) Consumer has experienced pain. (2) Grandmother and guardian included consumer on family insurance plan, but this has required out-of-pocket payment, in a situation of fixed income. (3) Consumer's family has expressed anger in response to the survey, clearly choosing to communicate frustration and inability to address the situation without help.

“Family Dental Coverage or Private Pay” Selected Comment 1 of 2
Has had pain because of no dental coverage. I put him on my insurance. Still [costs] a lot of money we don’t have. I think you could have come up with programs for adults. Your planning council don’t care about his pain. We’re on a fixed income and to pay a dentist is very costly. Signed by Grandmother and Guardian.

The second selected response to the open-ended question yielded a snapshot of a very specific health situation. (1) Incapacitated adult in a wheelchair faces dire consequences that result from conditions and medications that have a highly negative effect on the gums and teeth. (2) Consumer’s visits to the dentist four times per year demonstrates a commitment to saving what teeth are present, to enable consumer to eat. (3) Guardian/family member pays out-of-pocket for dental visits.

“Family Dental Coverage or Private Pay” Selected Comment 2 of 2
I am an incapacitated adult in a wheelchair. I visit my dentist 4 or more times per year to save all the teeth I have for eating. I have been on medications for seizures, which affect my gums and dental health. I always have to pay out-of-pocket expenses each time I visit the dentist. My guardian and family member pays the dentist.

Special Needs Dentistry

The area of SND brought forward multiple comments pertaining directly to the presence or absence of dental providers knowledgeable and skilled in procedures for optimizing care of individuals with developmental disabilities. Comment #1, shown below, indicates the following: (1) Use of special adaptive equipment in the form of a papoose board, in addition for extra “behavior charges” based upon patient movement, has proved stressful for the consumer and family. (2) Reportedly bad experiences with other dentists, has resulted in the consumer’s remaining with this doctor, whose fees are not within the patient’s control.

SND Selected Comment 1 of 4
My dentist says I need to come in every three months for a cleaning because i have gum disease. The Dentist has a flat body shaped board with big flaps off to the side that pull over me and Velcro my body to the board. They call it a papoose thing. So I am only able to move my head when i feel pain during the cleaning. My Mom kind of holds me too. We need to find another dentist for me. This one is just so expensive. He charges anywhere from $25-$100 for behavior fee, depending how much I move. It’s been $100 extra just for that. It’s been over $300.00 for my cleanings the last several months. He said things have gone up. I’ll say. So for me to continue to see this doctor, it cost me $100.00 a month to accumulate the $300.00 for my appointment. I have tried other dentists. Not good results. Thank you. Signed by consumer, as completed by mother of consumer

Comment 2 reveals that: (1) A visit to an SND clinic resulted in embarrassment and discomfort, causing the family to go to a private dentist. (2) Working with a recommended private dentist yielded a positive result, demonstrated by a referral to an oral surgeon for the removal of wisdom teeth. (3) Consumer’s family cannot afford dental fees, thus the patient’s mouth pain due to cavities, cannot be addressed, due to the cost of anesthesia. (4) The family worries about loss of teeth, and about gum disease. (5) Family caregiver expresses a desire for compassionate, well-educated dental providers.

SND Selected Comment 2 of 4
My child has been to a special needs dental clinic. They were negative and shame-based. They complained about her being unable to sit still and adverse reactions to being touched (Autism). Went by recommendation to a private dentist who was gentle and understanding. He made referral to have wisdom teeth removed with sedation. He then retired. Child is in need to have braces to prevent loss of front teeth, but this is not covered under AHCCCS / long-term care. Would be nice if services were covered on a case by case basis (need) and sedation for prevention such as cleaning were covered. My child also has two cavities at last check up. They cannot be treated without sedation. We cannot afford it. [She] Complains of mouth pain, and we are at a loss to get treated. Worry about loss of teeth, especially protruding front teeth and gum disease. Dentists need more compassion and education about the DD population.

Comment 3 indicates: (1) A perceived lack of familiarity with the special needs of patients with developmental disabilities, as reported by the family. (2) An inference by the respondent that the dentist "was not very caring." (3) The fact of the patient's inability to breathe and rapid heartbeat.

> SND Selected Comment 3 of 4
> Need to see a dentist who is familiar with special needs patients. Last visit, dentist was not very caring, and our daughter was gasping for air and her heart was beating very fast; we think she would've had heart failure.

Comment 4 indicates that (1) Consumer's family has had difficulty locating a dentist who works with AHCCCS patients in their area. (2) Family has participated in the Special Olympics dental check-up at scheduled events. (3) Most recent dental visit at Special Olympics performed billing functions incorrectly, resulting in the family having to pay hundreds of dollars out-of-pocket.

> SND Selected Comment 4 of 4
> It is difficult to find a dentist in our area that is in AHCCCS and will see a person with special needs. We usually take him during the Special Olympics state games. The last dentist we saw in this area screwed up the billing to AHCCCS and we ended up paying several hundred dollars out of pocket. Can't afford to let that happen again.

Obstacles to Care

Numerous obstacles to care were cited by respondents. Comment 1, shown below, indicates the following: (1) Consumer reports intermittent availability of dental care through AHCCCS. (2) Remote, rural local of consumer precludes easy access to urban-based special needs care.

> "Obstacles to Care" Comment 1 of 3
> In the past, dental work came through AHCCCS had only been available intermittently. It cannot be relied on to be there when needed. [It is located] in metropolitan area, and can't be easily accessed from rural areas. Phoenix is a 5-hour drive from my home.

Comment 2, the following points are offered: (1) There is a dearth of dentists and doctors available to serve the needs of clients who have special needs. (2) In 23 years, consumer visited the dentist on three occasions, with reportedly difficult experiences.

> "Obstacles to Care" Comment 2 of 3
> Not enough doctors available for special needs patients! [Visited the dentist] Only three times in 23 years. First dentist just looked, said to clean [would] have to strap down. The second dentist did strap down [the patient], [and it was an] awful experience. The third dentist placed the patient under sedation to clean and pull two teeth.

Comment 3 relates the situation of a particular consumer, facing the following issues: (1) Mentally challenged, and therefore unable to understand spoken directions. (2) Unable to hear or see. (3) Unable to sit still. (4) Resists being restrained.

> "Obstacles to Care" Comment 3 of 3
> Rosario is mentally challenged. Cannot do or understand oral directions and will not be able to physically follow or understand anyone. She is blind, deaf, and cannot sit still for any amount of time. And will not take too well to being restrained. For any more information feel free to call me.

Frequency of Cleaning

Many respondents noted the importance of frequent cleaning of the teeth by a dental professional. Comment 1, shown below reveals the following: (1) Swallowing difficulties since birth has resulted in the patient's swallowing plaque into the lungs, leading to aspiration pneumonia. (2) Antibiotics cleared the aspiration pneumonia. (3) Family placed consumer on a monthly cleaning process, calming the overall anxiety of the patient and producing better health.

"Frequency of Cleaning" Comment 1 of 3
Because of swallowing difficulties since birth I have not been able to control this and panicked each time I had a cleaning on a six-month schedule. This resulted in plaque being swallowed into my lungs and my developing aspiration pneumonia which fortunately responded to antibiotics. After this situation I went on a monthly cleaning so that the process was less traumatic and eventually even enjoyable. Now, as a monthly cleaning patient, they enjoy my visit and so do I.

Comment 2 reveals the following: (1) Mouth-breather condition generates more plaque than most patients have. (2) This level of plaque makes the gums recede and become overly sensitive. (3) Bite reflex necessitates sedation.

"Frequency of Cleaning" Comment 2 of 3
My son doesn't take anything by mouth and he's a mouth breather. The combination of the two conditions means that he builds more plaque than usual. The plaque causes gums to recede and become oversensitive. The thing saving his teeth right now is the care he gets at his particular group home. As a general rule dental care is the one thing most lacking in disabled children and adults. My son has a bite reflex and is unable to release at will. He has to be put to sleep. It costs a minimum of $130.

Comment 3 confirms the need of more frequent visits to the dentist, asserting that, regardless of developmental disabilities, all adults need to visit at least twice yearly for cleaning and examination.

"Frequency of Cleaning" Comment 3 of 3
In order to keep my teeth and gums in good condition I need to see my dentist at least every 6 months. Dental care on a regular basis is a must for everyone and it should not depend on whether or not you are developmentally delayed.

Relationship of Dental Hygiene to Overall Health

In concert with the 2000 Surgeon General Report on Oral Health Care in America, several respondents cited the relationship between dental hygiene, oral healthcare, and overall health. Comment 1 indicates the following: (1) Investing in dental care for low-income individuals helps identify issues early. (2) Certain infections that begin in the mouth are fatal.

Relationship of Dental Hygiene to Overall Health" Comment 1 of 4
I believe people with special needs with low income should be provided dental care. Preventive being most important before there are major issues. Certain mouth infections can kill you.

Comment 2 makes note of these points: (1) Many adults with developmental disabilities have been on medications, which are known to have a deleterious effect on the teeth and gums. (2) Prevention can reveal issues early, sometimes in time to prevent worsening of the teeth and overall health. (3) The status of adulthood does not preclude the need for dental care. (4) Financial burdens have been placed out of the state's hands and into the hands of each individual family. In many cases, this means "going without" for the consumers most in need.

"Relationship of Dental Hygiene to Overall Health" Comment 2 of 4
Please consider the fact that a lot of these adults have been and are on medications that cause decay. It's not that consumers are negligent of their teeth, but is something beyond their control. With regular preventive care they would be able to catch it before it requires a root canal. Just because [these individuals] are adults doesn't mean they don't need dental care. If anything, these adults need it more than typical adults. With the financial burden now placed on the families, even more dental care will be bypassed.

Comment 3 pleads with the reader for compassion and identification, citing the difference between citizens who do and do not have developmental disabilities. (1) Consumer is unable to chew food and swallows everything in his mouth. (2) Recent dental visit revealed six teeth that had to be removed, some below the gum line or on the exposed nerve, and most infected.

"Relationship of Dental Hygiene to Overall Health" Comment 3 of 4
My son needs assistance soon to have his mouth looked at because I want him to be able to chew his food and not just swallow everything that goes into his mouth. I have a fear he might choke one day. I hope you can put yourselves in his place. See you are able to go to a dentist or pharmacy to take care of yourselves or your loved ones, but my son or any brain-damaged individual is unable to. His

last visit resulted in having six teeth removed. Some were under the gum line or on the nerve (exposed) and most were black from infection. Put yourselves in his place, please. Signed, Mother/Guardian.

Comment 4 indicates that (1) Consumer has not seen the dentist for four to five years. (2) Consumer has difficult-to-reach veins, making IV sedation difficult. (3) Faces daily pain. (4) Family has no money for expensive procedures, notably anesthesia. (5) Down Syndrome, large tongue, small palate lead to inability of caregiver to see lower teeth. (6) Consumer has gag reflex, precluding easy brushing of teeth. (7) Chronic infection in mouth is feared to lead potentially to myocarditis.

"Relationship of Dental Hygiene to Overall Health" Comment 4 of 4
I have been really struggling to get my son's dental work. Last time he was able to go was 4-5 years ago when it was briefly covered at the AZ School of Dentistry. They were unable to start an IV there. He was trying to get up and has hard-to-reach veins . . . they sent him to an outpatient surgery clinic and he was sedated before arrival. He is in daily pain, but I'm unable to pay for those expensive procedures. Also, he has a very large tongue (Down Syndrome and small palate). I can't even see his lower teeth to brush them properly. I just guess where they are and use an electric brush. He has a strong gag reflex and vomits easily sometimes when brushing (or attempting). AZ School of Dentistry doesn't want to attempt treatment now because of prior difficulties. He's also terrified of dentists (and doctors) and Ivs. He has deformed and missing teeth (born without many). I'm afraid he'll lose what few he has if I don't do something soon. It's very bad for him to have this chronic infection in his mouth, as it could spread to his heart and cause myocarditis. People with disabilities are in desperate need for free or reduced services. Note: On front of survey: ""I am very pleased to receive this survey. There is a TREMENDOUS need for dental services for disabled people. Thanks! It gives us hope!

Medication Issues

Respondents indicated specific concerns pertaining to prescribed medication that causes damage to the teeth and gums. These concerns, added to issues of delayed or absent preventive care, dental treatment, and financial constraints precluding dental care, have resulted in significant health risks.

Comment 1 indicates: (1) Persistent headaches and mouth pain lasting for years, apparently resulting from prescribed seizure medication. (2) No preventive dental care was available, based upon financial constraints.

"Medication Issues" Comment 1 of 3
Most of my teeth [have] caps or bridges. I only was able to get them done because my sister paid for it. I suffered headaches, and mouth pain for years. I take medicine for seizures, and that medicine affects the health of my gums. I didn't get preventative dental care for years because I was poor and couldn't afford it. Had I had that preventative care, I might have prevented much of my dental work from having to be done.

Comment 2 makes note of the following: (1) Anti-convulsant medication has caused damage to teeth and gums. (2) Patient is unable to convey the message of pain or need.

"Medication Issues" Comment 2 of 3
My teeth and gums are in bad shape because of medication. I was on Dilatin [anti-convulsant medication], I have two sets on the bottom. I do not talk, so no one knows if I have pain. I need the help I've been getting.

Comment 3 relates the situation of anti-seizure medication, resulting in gingival inflammation.

"Medication Issues" Comment 3 of 3
I take anti-seizure medication which causes gingival inflammation.

Conclusions

The 2011 Update of the original report of Oral Healthcare for Adults with Developmental Disabilities, developed in 2006, has emphasized multiple facets of the new reality of oral healthcare challenges faced by consumers and their families. A review of professional and consumer/family perspectives indicates a range of issues and concerns, as well as opportunities for establishing platforms with rigorous standards in place for protecting Arizona's citizens. The following conclusions can be drawn from the 2011 Report:

1. A uniformly high level of concern has been expressed by dental professionals, stakeholder professionals representing multiple service agencies and departments, and adult consumers and their families, regarding the emergency situation that adults with developmental disabilities currently face in Arizona. Many adult consumers have already abandoned their quest for affordable oral healthcare, based upon very limited income and the absence of public funding to support necessary preventive care and treatment.
2. A review of the literature indicates the severe health consequences of neglecting oral healthcare, particularly for the highly vulnerable population of adults with developmental disabilities.
3. The economic crisis facing the nation and the state has resulted in dire consequences regarding the allocation of fiscal resources to meet the prevention and treatment needs of adult consumers in Arizona. The crisis threatens agencies and for-profit businesses whose clients are adult consumers with developmental disabilities. Resources exist for serving the adult population of individuals with developmental disabilities, but are threatened by the absence of all public funding for adults. One such example is the scheduled closure of Gompers Dental Clinic in December, 2011.
4. At the system level, the oral healthcare of adults with developmental disabilities lacks standards and protocols for ensuring preventive services or needed treatment. The absence of state funding for necessary dental procedures for adults exacerbates a health hazard faced by citizens who are already vulnerable, based upon physical, health, and practical limitations not of their own choosing.
5. For multiple years, Arizona has been building capacity in the form of educational programs dedicated to oral healthcare, including services to individuals with developmental disabilities. The Director of the Dental Program at A.T. Still University, Dr. Maureen Romer, is President-Elect of the Special Care Dentistry Association, and is a noted authority in the field. Midwestern University is soon to graduate its first class of dentists. Numerous training programs for dental hygienists, including many community colleges, exist in Arizona. The Arizona Dental Foundation has repeatedly sponsored SND training for Continuing Education credits for dentists statewide. The Arizona Department of Health Services has participated actively as a grantee of the Robert Wood Johnson Foundation dental care initiative over a period of years. Dr. Robert Birdwell, Director of Dentistry for the Arizona Health Care Cost Containment System, is an expert in oral healthcare, as well.
6. Despite the documented evidence of dentists who have been trained in SND, there appears to be little if any incentive for these dentists to build a practice around adults with developmental disabilities, based upon financial constraints, including insufficient reimbursement for services; labor-intensive requirements of their offices, and the challenge of treating individuals with special needs.
7. A structured, intentional initiative that draws together and shapes into a system the multiple resources, including but not limited to advocacy organizations, dental professionals, and other stakeholders, is absent and very much needed in the state. Under the current conditions, a requirement for needed change is an articulated, easy-to-understand initiative that seeks to serve individuals with developmental disabilities. Such an initiative of necessity must include strategic partnership from the private and public sectors, ensuring collaborative, cooperative, and mutually beneficial strategic direction for the purpose of supporting the target population.
8. State-level individual program plans for consumers with developmental disabilities do not routinely incorporate measures for oral healthcare, and any inclusion of measures must be put forward and defended aggressively by self-advocates and caregivers.
9. Dentists in private practice are routinely urged by members of their communities to donate services to individuals with developmental disabilities. Further, there is an absence of approaches beyond narrowly focused solutions that address the needs of one or two people, rather than the vast, county-level or state-level needs of thousands of Arizonans.

Preface to Recommendations

This study of oral healthcare for adults with developmental disabilities has explored the reality of a specific healthcare crisis having extensive public and private impact on a highly vulnerable population, in addition to the larger community and societal systems to which these individuals and their families belong. In an effort to examine the issue thoroughly, multiple vantage points directly associated with the sphere of study have been examined, including:

1. Professional dental assessment of the general oral and medical impact of delaying or neglecting oral healthcare on any citizen, and the exacerbated results for individuals of the highly vulnerable population under study.
2. Budgetary impact of unfunded oral healthcare for individuals with developmental disabilities, amounting to a transfer of expenditure from dental provider to emergency room care, typically treating symptoms rather than causes, and further damaging the body and raising the cost of long-term care.
3. Contextual factors, notably the following:
    a. Severe reduction of public and other funding for oral healthcare, with anticipation of continued limitations on public funding
    b. Need for education of decision makers and the public at large regarding the inextricable connection between oral health and general medical well being
    c. Systemic absence of incentives, in conjunction with the presence of disincentives, for dental professionals to treat adults with developmental disabilities
    d. Absence of system-level approaches to diagnosis and delivery of oral healthcare for Arizona citizens age 18 and older, within the framework of eligible income levels
    e. Potential for emphasizing oral healthcare into the Individual Service Plans (ISP) of adults on a state-wide and agency-wide basis
    f. Dearth of accessible professional dental care in remote, rural locations

Strategic Approach for Recommendations

1. Incorporate a version of a best practice recognized by the Center for Disease Control (2008), in systematic oral health surveillance, such as that of the North Dakota Oral Health Surveillance Program.
2. Initiate a statewide program of caregiver training, such as that described by Glassman (2006) in the State of Florida, incorporating coaching of caregivers, and systematic re-training on a periodic basis, to address employee turnover.
3. Build a statewide campaign to create awareness, disseminate knowledge, and clarify the extent of need.
4. Develop an accurate and comprehensive database documenting a “clean and screen” campaign.
5. Formulate and maintain periodic updates of a complementary database of capacity (dentists available to deliver services as part of a highly publicized, concerted campaign).
6. Simplify delivery of initial, baseline services, consisting of (a) Diagnostic screening, (b) Cleaning of teeth, and (c) Caregiver training and support materials, to serve all adult Arizonans with developmental disabilities.
7. Provide fiscal and non-fiscal incentives to dental professionals, contributors, caregivers, and adult consumers themselves. Possible incentives might include, but not be limited to, tax incentives and professional recognition for dental professionals, adjusted insurance fees for proactive care, and awards for purchasing goods and services for caregivers.
8. Actively pursue an innovative initiative in response to segments of (2010) “The Patient Protection and Affordable Care Act,” to formalize training and capacity in Arizona for growing the field of dentistry for adults with developmental disabilities.

9. Identify and develop opportunities to share with elected officials and other government leaders the importance of oral healthcare as a way of maintaining health and well-being, especially for citizens with developmental disabilities.

10. Establish an alternative stream of support, in the form of supporting foundation grants, community, business, and individual funding through tax-free opportunities that result in long-range, sustainable Oral Healthcare to adults 18 years of age and older.

11. Develop a support, reform and action commission composed of dental professionals, caregivers, and consumers to support oral healthcare for Arizonans with developmental disabilities.

Supporting Tactical Methods for Recommendations

1. Build capacity through opportunities specified in the (2010) Patient Protection and Affordable Care Act, specifically the establishment of a Consortium of Providers for SND, training for caregivers, and establishing a major presence in the Oral Healthcare arena in the form of a public-private partnership established to deliver a state-of-the-art care to the population of individuals with developmental disabilities.

2. Apply the Thomas F. Gilbert (2007) Model of Human Performance Engineering to address gaps in Knowledge, Instrumentation, and Motivation, and establish community-specific models that address this significant need.

3. Build and award recognition and funding for replicable, community-based models contributing to the ongoing pursuits of simplified implementation of models for sustainability of oral health care baseline services in a wide range of community types.

The recommendations in the following section are based upon strategic, system- and process-level change. Employing the Gilbert (2007) Model of Human Performance Engineering recommendations call for proactive change in Knowledge (through training and education), Instrumentation (through tools), and Motivation (through incentives), as shown in Chart 149.

Recommendations

Chart 149: Model of Human Performance Technology

Knowledge Deficit	Instrumentation Deficit	Motivation Deficit
Can be addressed by	***Can be addressed by***	***Can be addressed by:***
Training and Education	Tools and Instruments	Incentives (monetary and/or non-monetary)

Address Gaps in Knowledge

Gilbert's Human Performance Engineering Model suggests that gaps in Knowledge are best addressed by providing Training and Education. There has long existed a division between the fields of medicine and dentistry. That oral healthcare is the "gateway" to effective general health, is a little known fact. To address this particular gap in knowledge, the following recommendations are provided.

Establish a major, statewide awareness campaign that clarifies the link between Oral Healthcare and general health, targeting adults with developmental disabilities, using a specific timeline, through the following specific components:

a. High Profile task force with a mission to simplify and amplify the message.
b. Integration of business, government, and community leaders identifying individuals who can lend visibility and support, as well as persons whose families share a commitment to serving persons with developmental disabilities.
c. Relationship among structured subcommittees representing small, medium, large communities, and urban, suburban, and rural communities and their unique needs.
d. Documentation of need, and corollary resource base, encompassing capacity in medical/dental resources, funding support from service organizations, foundations, and individual participation in a community-based structure.
e. Event-based, measured timeline that identifies milestones along a specified path that is project-managed.
f. Public relations campaign that features newsworthy articles, radio and television publicity, internet-based and social network-driven communiqués, and integrated messages to local, county, and state government personnel and elected officials.
g. Training materials for caregivers, family members, and adult consumers themselves, to support accurate, easy instruction on prevention and care for oral health.

Address Gaps in Instrumentation

Gilbert's Human Performance Engineering Model suggests that gaps in Instrumentation are best addressed by providing tools that make delivery of services possible, or even probable. In this instance, instrumentation encompasses a wide range of elements associated with technical delivery of services.

It should be noted that funding of instrumentation-related elements specified below remains an issue, but must not be overlooked when specifying gaps in the system and the need to plan a response to such elements.

Support the awareness and database campaign through the provision of applicable technology for serving the Oral Healthcare needs of adults with developmental disabilities, through each of the following components:

a. Assistive technology to facilitate supportive dental treatment for individuals with developmental disabilities. The distribution of mechanical toothbrushes, flossers, and instructional materials that clarify simple methods of preventing problems with teeth

b. Service delivery hardware, software, and transport units, including mobile dental service units, tele-dentistry mechanisms that aid in delivering streamlined forms of diagnosis and treatment, to reduce the mileage for families needing care for individual adult consumers

c. Easy-to-use whiteboard-based checklists for use, where appropriate, to facilitate care and follow-through for adult consumers and caregivers.

Address Gaps in Motivation, including Funding

Gilbert's Human Performance Engineering Model suggests that gaps in Motivation are best addressed by providing incentives (monetary or non-monetary, as the situation dictates) that encourages, induces, and/or inspires people to pursue courses of action that contribute to the performance objective of cleaning and screening every adult consumer in Arizona who has developmental disabilities.

Stimulate desirable and necessary participation in the long-range campaign by providing monetary and non-monetary incentives to dentists, dental hygienists, caregivers, and adult consumers, through:

a. Development of a "Fee Share" program that facilitates contributions by non-dental contributors, to supplement the delivery of services by Oral Healthcare professionals.

b. Establishment of one or more non-profit organizations, as appropriate, to gather funding from foundations, service organizations, and individuals, for purposes of ensuring systematic Oral Healthcare prevention and treatment for adults with developmental disabilities.

c. Funding mechanisms through structured support, utilizing: foundation grants, service organization funding, and individual funding support, both large-scale and small-scale/ incremental contributions, to support a focused, campaign style baseline "Clean and Screen" initiative that demonstrates and helps build a baseline of care in communities statewide.

d. Establish mechanisms for citizen and organizational contributions to dental care, rather than relegating all responsibility for fee reduction and service donation to dentists.

e. Proper third-party coding of services that leads to proper and timely monetary compensation, accurately reflective of the services delivered in terms of actual time and associated costs of providing prevention and treatment.

f. Support of opportunities to build the dental practice of participating professionals, in association with services delivered to the population of patients having developmental disabilities.

g. Structured reward systems that fund the development of post-graduate specialties in dentistry that serves individuals with developmental disabilities.

h. Systematic, competitive rewards for caregivers and adult consumers in return for engaging in, documenting, and demonstrating results of prevention, based upon oral healthcare practices taught statewide. Rewards for prevention would be one method of rewarding patients for avoidance of health challenges based in part upon neglect of oral health.

i. Statewide recognition of donor organizations [notably, individual contributors, service organizations, non-profit organizations, and foundations] for contributing to prevention or "clean and screen" endeavors.

j. Organized, well-publicized, event-based campaigns for prevention that begins with adult consumers with developmental disabilities and eventually expands to general population of the State. (The reverse of the usual pattern, whereby a reduced version of a larger, more effective campaign is imitated for the developmental disability communities, rather than initiating the campaign with their needs specifically emphasized.)

k. Enlisting dental practitioners, including dentists and dental hygienists, to participate in a service campaign to screen patients on specific dates across the State to gain data on adults with developmental disabilities.

l. Documented formulation of regional and local database specifying oral healthcare need, provider care, and community support.

m. Development of multiple specific community-based models that demonstrate potential for continuation and replication in communities having similar composition and capacity.

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Glossary of Terms

Advanced Dental Hygiene Practitioner (ADHP, or Mid-Level Provider). "Dental hygienist who has graduated from an accredited dental hygiene program and has completed an advanced educational curriculum approved by the American Dental Hygienists Association, which prepares the dental hygienist to provide diagnostic, preventive, restorative, and therapeutic services directly to the public." (Cattrell, 2007).

Analysis of Variance (ANOVA). Statistical tool that distinguishes between random and systematic types of variability, determining the effect that independent variables have on dependent variables when performing a regression analysis (Investopedia, 2011).

Bonferonni Correction. A type of multiple comparison statistical test that corrects against falsely significant results based upon multiple tests performed. (Investopedia, 2011).

Chi-Square Statistic. A statistical test used to distinguish between expected and actual results based upon random independent variables. (Investopedia, 2011).

Emergent Taxonomic Analysis. A procedure for classifying raw, qualitative feedback that derives classifications from participant or interviewee responses to open-ended questions, without using any pre-ordained taxonomy. (Murphy, 2011).

Mobile Dentistry. The practice of delivering dental services through the use of self-contained, vehicular dental office units, frequently utilized to serve low-income and corporate offices, for the purpose of providing services to remote locations and in a time-efficient manner.

Pearson's Product-Moment Correlation. A statistical procedure using measures between -1 and 1 that reveals the degree of linear dependence between two independent variables. (McDonald, 2008)

Spearman's Rank Correlation. In statistics, the non-parametric (non-normal distribution assumption) equivalent of correlation, determining the degree of relationship between two variables. A ranking procedure is used, followed by a sequence of tests of significance. (McDonald, 2008).

Special Needs Dentistry (Special Care Dentistry). "Branch of dentistry that provides oral care services for people with physical, medical, developmental, or cognitive conditions which limit their ability to receive routine dental care." Special Care Dentistry Association (2011).

Tele-dentistry. The provision of dental services that incorporate the transmission of digital images to share x-rays to dental professionals who can diagnose remotely, thereby reducing the number of direct personal visits needed to perform dental procedures.

Appendices A – D

Appendix A: Cover Letter and Online and Paper Questionnaire

Appendix B: Interview and Focus Group Protocols

Appendix C: Adult Benefits in Medicaid: FY 2002 – 2010

Appendix D: Compendium of Consumer Comment in Response to Open-Ended Survey Question

Appendix A: Cover Letter and Online and Paper Questionnaire

On ADDPC Letterhead – Sent June 3, 2011

Dear Survey Participant,
The Arizona Developmental Disabilities Planning Council has engaged a Phoenix-based firm to perform an update of its 2006 study of Oral Healthcare for Adults with Developmental Disabilities. The 2011 study, due to be completed this summer, comes at a particularly important time, given widespread reductions for Oral Healthcare nationwide. The 2011 study will provide a framework for dialogue and decision making about dental care for adults 18 years of age and older with Developmental Disabilities in Arizona.

We invite you to participate in this vitally important survey, sponsored by the Arizona Developmental Disabilities Planning Council. The survey is **voluntary.** All responses are **anonymous** and **confidential**, and will be presented in summary form, with no individual answers identifiable. **Your completing this survey does not affect services received by the Division of Developmental Disabilities, now or in the future.**

Through the cooperation of the Department of Developmental Disabilities, we are seeking your views, as a consumer of Oral Healthcare, through this survey. You can take the survey in either of two ways:

- Complete the paper-based survey enclosed, and return, using the self-addressed, stamped envelope

or

- Complete the survey online, using the following link:

In English:
https://www.surveymonkey.com/s/SCMTXJH

In Spanish:
https://www.surveymonkey.com/s/SCCHGBC

We respectfully request that you complete the survey by no later than June 30, 2011.

Thank you for taking part and providing your views.

Sincerely,

Larry Clausen
Executive Director
Arizona Developmental Disabilities Planning Council

Sheila E. Murphy, Ph.D.
President
Sheila Murphy, LLC

Oral Healthcare Survey of ADULTS (Age 18+) with Developmental Disabilities

This Survey, sponsored by the Arizona Developmental Disabilities Planning Council, is voluntary. All responses are anonymous and will be summarized. Your completing this survey does NOT affect services received by the Division of Developmental Disabilities.

Oral Healthcare Survey of ADULTS (Age 18+) with Developmental Disabilities

The Arizona Developmental Disabilities Planning Council would like to learn more about your oral healthcare. **Your answers will be kept confidential.**

Carefully answer these questions yourself or with the help of a person who can assist you. **All questions refer to the ADULT with Developmental Disabilities:**

1. I am completing this survey:
   _____ About myself (as a self-advocate)
   _____ For a family member
   _____ As a caregiver

In the next section, please tell us about your age, gender, ethnic background, and residence.

2. My age:
   (Please check one)
   _____ 18-30
   _____ 31-40
   _____ 41-50
   _____ 51-60
   _____ 61-70
   _____ older than 70

3. I am a:
   _____ Male
   _____ Female

4. I am
   _____ Hispanic
   _____ White, Non-Hispanic
   _____ African-American
   _____ Native American
   _____ Asian
5. I live in:
   (Please check one)
   _____ Phoenix
   _____ Tucson
   _____ Glendale
   _____ Mesa
   _____ Chandler
   _____ Scottsdale
   _____ Flagstaff
   _____ Yuma
   _____ Florence
   _____ Casa Grande
   _____ Holbrook
   _____ Nogales
   _____ Winslow
   _____ Paradise Valley
   _____ Page
   _____ Queen Creek
   _____ Quartzsite
   _____ Safford
   _____ San Manuel

_____ Thatcher
_____ Tolleson
_____ Tombstone
_____ Winkelman
_____ Other City or Town
_____
Name of Other City or Town

6. I live in

_____ Ak Chin Indian Community
_____ Cocopah Tribe of Arizona
_____ Colorado River Indian Tribes
_____ Fort McDowell Yavapai Nation
_____ Fort Mojave Indian Tribe
_____ Gila River Indian Community
_____ Havasupai Tribe
_____ Hopi Tribe of Arizona
_____ Hualapai Indian Tribe
_____ Kaibab Band of Paiute Indians
_____ Navajo Nation
_____ Pascua Yaqui Tribe
_____ Quechan Tribe
_____ Salt River Pima-Maricopa Indian Community
_____ San Carlos Apache Tribe
_____ San Juan Southern Paiute Tribe
_____ Tohono O'odham Nation
_____ Tonto Apache Tribe
_____ White Mountain Apache Tribe
_____ Yavapai-Apache Nation
_____ Yavapai-Prescott Tribe
_____ Other Tribal Community
_____Name of Other Tribal Community

7. I live:
_____ Independently
_____ In other supported living arrangement or college dormitory
_____ With family
_____ In a group home or foster home
_____ In an Intermediate care facility (ICF/MR)

In the next section, please tell us about your education, employment, and insurance coverage.

8. I have completed the following education:
<u>High School</u>
Check one:
_____ High School Diploma
_____ General Education Development (GED)
_____ Certificate of High School Completion
_____ Did not complete High School

9. <u>Post-Secondary</u>
Check highest level:
_____ Currently attending non-traditional educational program
_____ Post-Secondary Vocational Certificate
_____ Associate of Arts or Science
_____ Bachelor's Degree (BA, BS)

_____ Master's Degree (MA, MS)
_____ Doctoral Degree (PhD or EDD)
_____ Other (Describe below)
_____

10. I have income from the following sources:
Check all that apply:
_____ Social Security or SSI
_____ Disability
_____ Work / Employment Pay
_____ Other (Describe below)
_____

11. Sometimes I work as a volunteer.
_____ Yes
_____ No

12. I have a paying job. I receive money from my job/employer.
_____ Yes
_____ No

13. I receive dental care benefits through my work.
_____ Yes
_____ No

14. I have the following medical insurance coverage:
_____ AHCCCS (Arizona Health Care Cost Containment System)
_____ ALTCS (Arizona Long-Term Care System)
_____ Medicare
_____ Private Medical Insurance
_____ Other (Describe below)
_____

15. I have the following dental insurance coverage:
_____ Public (Medicare/Medicaid/AHCCCS)
_____ Private (from a private carrier)
_____ None

In the next section, please tell us about oral health, if I had teeth removed, and general health.

16. The number of my permanent teeth removed because of tooth decay or gum disease is:
NOTES: This includes teeth lost to infection, but not teeth lost for other reasons, such as injury or orthodontics. This also includes wisdom teeth removed because of tooth decay or gum disease.
_____ 1 to 5 removed
_____ 6 or more, but not all, removed
_____ All removed
_____ None removed

17. I have all of my teeth:
_____ Yes
_____ No

18. I have no teeth:
_____ Yes
_____ No

19. If yes, check one:
    _____ I wear full dentures.
    _____ I do not wear dentures

20. I would describe the condition of my mouth and teeth as:
    _____ Very good
    _____ Good
    _____ Fair
    _____ Poor
    _____ Don't know

21. I would describe the condition of my gums as:
    _____ Very good
    _____ Good
    _____ Fair
    _____ Poor
    _____ Don't know

22. I have the following problems with my teeth:
    Check all that apply:
    _____ Pain
    _____ Cavities
    _____ Broken or missing teeth that impair my ability to eat
    _____ Crooked teeth or teeth that need braces
    _____ Teeth that need cleaning
    _____ Gum problems
    _____ Grinding, soft, or falling-out teeth
    _____ Root canal or nerve problems with teeth
    _____ No problems with teeth
    _____ Don't know

23. During the past 6 months, I have had the following problems that lasted more than a day:
    Check all that apply:
    _____ Difficulty eating or chewing
    _____ Difficulty eating solid foods
    _____ Difficulty swallowing
    _____ Bleeding gums
    _____ Mouth pain
    _____ Sores in my mouth
    _____ Loose teeth not due to injury
    _____ Loose teeth due to injury
    _____ Decayed teeth
    _____ Broken or missing fillings
    _____ Dry mouth
    _____ Bad breath
    _____No known problems

24. I have a problem with my teeth and/or gums that makes it painful to eat:
    _____ Yes
    _____ No

25. The following situations apply to me in the dentist chair:
    Check all that apply:
    _____ I have difficulty sitting still for a long time.
    _____ I have difficulty keeping my mouth open for a long time.
    _____ I have difficulty with equipment that holds open my mouth.
    _____ I have difficulty with florescent lighting.

_____ I have difficulty with certain noises.
_____ I am very afraid of dental work.
_____ Other (Please describe):
_____

26. The following health conditions apply to me:
Check all that apply:
_____ I have a history of diabetes.
_____ I have a history of high blood pressure.
_____ I have a history of heart disease.
_____ I have a history of difficulty in breathing.
_____ I have a history of contractures (shortening or hardening of muscles).
_____ Other (Please describe):
_____

In the next section, please tell us about the care of your teeth.

27. I am able to care for my teeth:
_____ By myself. I brush my teeth very well.
_____ With difficulty: It is hard for me to brush appropriately
_____ With assistance of a caregiver
_____ A caregiver must do this for me.

28. I brush my teeth:
_____More than 3 times a day
_____ 3 times daily
_____ 2 times daily
_____ 1 time daily
_____ Less than once a day

29. I floss my teeth:
_____More than 3 times a day
_____ 3 times daily
_____ 2 times daily
_____ 1 time daily
_____ Less than once a day
_____ Once or twice a week
_____ I never floss my teeth

30. I use the following:
_____ Regular toothbrush
_____ Special grip for toothbrush
_____ Electric toothbrush
_____ Toothpaste squeezer
_____ Toothpaste dispenser
_____ Power or special flosser
_____ Other (Please name)
_____

31. The last time I visited the dentist or dental clinic for any reason (including visits to dental specialists, such as orthodontists):
_____ Within the past year (any time less than 12 months ago)
_____ Within the past 2 years (more than1 year but less than 2 years ago)
_____ Within the past 5 years (more than2 years but less than 5 years ago)
_____ 5 or more years ago
_____ Never

32. I still see the dentist I visited before:
    _____ Yes, I see the same dentist.
    _____ No, I do not see the same dentist.
    _____ I once visited a dentist and I did not go back

33. My reason for visiting a dentist the last time was:
    Check all that apply:
    _____ Regular checkup
    _____ To have teeth cleaned
    _____ To have teeth filled
    _____ To have teeth pulled or other surgery
    _____ Toothache
    _____ Adjustment or repair of a denture
    _____ To have a denture made
    _____ For a prescription
    _____ Bleeding gums or periodontal disease
    _____ Loose teeth
    _____ Problems with 3rd molar (wisdom teeth)
    _____ Don't know
    _____ Some other reason (Describe)
    _____

34. The following have stopped me from going to the dentist:
    Check all that apply:
    _____ On a waiting list for dental care.
    _____ No transportation to dentist
    _____ No dentist close to where I live.
    _____ No money to pay for dental care.
    _____ Insurance plan does not pay for dental care.
    _____ Concern about discomfort or pain
    _____ I need someone to go with me; no one is available.
    _____ I am afraid to go to the dentist.
    _____ Other (Please describe)
    _____

35. The last time I had my teeth cleaned by a dentist or dental hygienist:
    _____ Within the past year (any time less than 12 months ago)
    _____ Within the past 2 years (More than 1 year but less than 2 years ago)
    _____ Within the past 5 years (More than2 years but less than 5 years ago)
    _____ 5 or more years ago
    _____ Never

36. My reason for seeing the dentist or dental hygienist the last time was:
    Check all that apply:
    _____ Regular cleaning
    _____ Stained, yellowed, or blackened teeth
    _____ Fluoridation treatment of my teeth
    _____ Gum problems
    _____ Regular preventive care
    _____ Don't know

37. The last time I went to the Emergency Room for dental pain or issues was:
    _____ Within the past year (any time less than 12 months ago)
    _____ Within the past 2 years (More than1 year but less than 2 years ago)
    _____ Within the past 5 years (More than2 years but less than 5 years ago)
    _____ 5 or more years ago
    _____ Never

38. My reason for visiting the Emergency Room for dental issues the last time was:
    Check all that apply:
    _____ Difficulty or discomfort eating or chewing
    _____ Difficulty or discomfort eating solid foods
    _____ Difficulty or discomfort swallowing
    _____ Bleeding gums
    _____ Mouth pain
    _____ Sores in my mouth
    _____ Loose teeth not due to injury
    _____ Loose teeth due to injury
    _____ Decayed teeth
    _____ Broken or missing fillings

39. The outcome of my visit to the Emergency room was:
    _____ I was hospitalized
    _____ I was referred to a dentist
    _____ I was prescribed medication
    _____ Other (Please describe)
    _____

40. Other information I want to share about my dental care needs:

    _____
    _____
    _____
    _____
    _____
    _____
    _____
    _____
    _____
    _____

Thank you for answering these questions. Your answers will be very important to this report. The results of this study of oral healthcare for adults with developmental disabilities will be available to you through the Arizona Developmental Disabilities Planning Council (ADDPC).

Appendix B: Interview and Focus Group Protocols

Interview Protocol for Special Needs Dentistry Training Program

The following interview questions will be asked of a sample of individual dentists representing selected urban and rural parts of Arizona, who have received training in Special Needs Dentistry through Arizona-based agencies. Included in the sample will be (1) dentists who have delivered oral healthcare to adults with special needs, and (2) dentists who have not delivered oral healthcare to adults with special needs, following the training program. All questions pertain to patients having special needs.

INTERVIEW WILL BE PRECEDED BY EXPLANATION THAT THIS IS AN INDEPENDENTLY CONDUCTED RESEARCH STUDY, AND ALL RESPONSES WILL BE ANONYMOUS AND SUMMARIZED SO THAT NO ONE'S COMMENTS WILL BE IDENTIFIED BY PERSON.

1. Have you participated in training to treat special needs patients?
2. When did this training occur?
3. How many hours did the training last? Was the training in-person, hands-on, or online? How many hours of each?
4. What agency provided this training?
5. What was the most valuable learning you received from participating in this training program?
6. Based upon your experience following the training, what, if anything, should have been covered in the program that was not? Please explain.
7. Would you recommend that other dentists enroll in the training to treat special needs patients? Why or why not?
8. To what extent have you applied the learning that you received?
9. How many special needs adult patients have you seen on a monthly basis since you received the training?
10. What, if anything, has posed a challenge or issue regarding seeing these individuals?
11. Has it been necessary to purchase special equipment to serve individuals? Has the purchase and maintaining of this equipment posed an obstacle to serving these adults with DD?
12. What, if anything, has prevented you from seeing special needs patients since your training?
13. Are there any system-level supports (billing, funding, insurance-related) that need to be reviewed or adjusted, to enhance oral healthcare for individuals? Please explain.
14. Are there any in-office practices or procedures that you have implemented to date to enhance service and care for individuals? Please explain.
15. To what extent do you believe that tele-dentistry plays a potential role in the oral healthcare of individuals? Would you comment on the following:
    a. Potential for specialty care in rural areas
    b. Possible application for initial diagnosis
    c. Consultation in specialty areas regarding treatment plans
    d. Issues regarding investment in equipment for dental offices to participate
16. Would you be willing to provide services to individuals at no charge or at reduced charge? If so, why? If not, why not?
17. What, if any, additional considerations should our study of Oral Healthcare for Adults with Developmental Disabilities address?

Focus Group Protocol: Stakeholder Professionals involved in the Delivery of Oral Health Care to Adult Persons with Developmental Disabilities (DD) in Arizona

The following questions are proposed for use in guiding focus groups with stakeholder professionals associated with Oral Healthcare for Arizona DD adults:

1. What preventive measures has your agency put into practice for oral healthcare for adults with developmental disabilities?
2. What training does your agency provide or obtain to help professionals assist adults with disabilities with preventive measures to ensure oral healthcare?
3. Is oral healthcare included in the IPP for adults with Developmental Disabilities?
4. What equipment does your agency provide or obtain to help with prevention?
5. How does your agency address emergency oral health care needs with your DD clients? What measures have been successful? What measures have been unsuccessful?
6. What recommendations do you have for your local area regarding emergency oral healthcare?
7. What partnering agencies assist you in contributing to oral healthcare for adults with developmental disabilities?
8. To the best of your knowledge, what have DD adults done to get help when regular oral healthcare has not been funded? Where have they gone? What has occurred as a result of this course of action?
9. Are there short-term approaches to helping DD adults with oral healthcare that should be addressed during this time of budgetary crisis? What do you believe should be done at the personal and system levels?
10. How does your organization currently partner with other organizations to bring about oral healthcare benefits to DD adults in Arizona?
11. Does your agency have a sufficient number of local dental practitioners who schedule care for adults with DD within a reasonable timeframe?
12. Do you have a success story to share regarding prevention and/or treatment in the area of oral healthcare for DD adults in Arizona? What does this story illustrate about the potential benefits and service to this population?
13. What do you believe is the top priority for delivering oral healthcare to DD adults in Arizona?
14. What are the possible consequences of not providing oral healthcare for DD adults in Arizona? What health considerations exist? What budgetary considerations exist?
15. What education is needed about oral healthcare for DD adults? Who needs to receive it?
16. Recognizing the current financial crisis, what creative approaches do you believe should be taken to benefit the adult DD population regarding oral healthcare, both now and in the coming 3-year period?
17. Are you familiar with tele-dentistry? Does this practice have application to the current situation in oral healthcare for DD adults? Why?
18. What ideas pertaining to donation of services would be possible to enhance the opportunity to increase the level of oral healthcare services for Arizona's DD adult population?
19. Can you think of any model programs for oral healthcare delivery to DD adults in other locations that would be instructive for Arizona to use in tailoring our own system?
20. If you were to recommend one action that would accomplish the most right now to address the challenge associated with oral healthcare for DD adults, what would that be?

Interview Protocol: Caregivers of Adult Persons with Developmental Disabilities (DD) in Arizona – Oral Health Care

The following questions are proposed for use in guiding interviews with caregivers of DD adults in Arizona:

1. Is oral healthcare included in the IPP for adults with Developmental Disabilities?
2. Do you assist adults with Developmental Disabilities with teeth cleaning? If you answered "yes," what specific assistance do you provide? If you answered "no," what role do you play in ensuring that clients' oral healthcare is addressed on a routine basis? Please be as specific as you can regarding brushing, flossing, or other activities.
3. Have any of your adult DD clients experienced problems with their teeth over the past year? If you answered "yes, what procedures have been followed to obtain assistance for them? If you answered "no," what procedures do you follow to find out about any oral healthcare issues?
4. How frequently do your adult DD clients see a dental professional? What type of dental professional have your clients seen within the past year:
    a. Dentist
    b. Dental hygienist
    c. Other (Please specify)
5. Have any of your adult DD clients experienced an emergency that indicated oral health-related issues within the past year? If you answered "yes," briefly describe what actions were taken and what resulted from those actions.
6. Is there any additional information that you believe would be helpful for us to explore in our study of Oral Healthcare for Adults with Developmental Disabilities in Arizona?

Appendix C: Adult Dental Benefits in Medicaid: FY 2002 – 2010

ADULT DENTAL BENEFITS IN MEDICAID: FY 2002-2010									
	2002	2003	2004	2005	2006	2007	2008	2009	2010
Alabama	None								
Alaska	Emergency				Limited				
Arizona	Emergency								None
Arkansas	None						Limited		
California	Full			Full--Capped					
Colorado	None								
Connecticut	Full								
Delaware	None								
Florida	Emergency								
Georgia	Emergency								
Hawaii	Emergency					Limited			
Idaho	Emergency								
Illinois	Limited								
Indiana	Full	Limited							
Iowa	Limited								
Kansas	Emergency								
Kentucky	Limited full???								
	2002	2003	2004	2005	2006	2007	2008	2009	2010
Louisiana	Limited-Dentures and Pregnant								
Maine	“Urgent” Care								
Maryland	Emergency								
Massachusetts	Limited		Emergency		Limited				
Michigan	Full	Limited		Full				Emer-gency	Full
Minnesota	Full	Limited							
Mississippi	Emergency								
Missouri	Limited			None					
Montana	Limited								
Nebraska	Limited								
Nevada	Palliative								
New Hamp	Emergency								
New Jersey	Full								
	2002	2003	2004	2005	2006	2007	2008	2009	2010
New Mexico	Full		Limited						
New York	Full								
N Carolina	Limited								

N Dakota	Full								
Ohio	Limited								
Oklahoma		Emergency							
Oregon	Limited								
Pennsylvania	Full								
Rhode Island	Limited								
S Carolina	Emergency								
S Dakota	Full								
Tennessee	Emergency								
Texas	None								
Utah	Emergency				Limited				
Vermont	Limited								
Virginia**	None								
Washington	Full	Limited				Full			None
	2002	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
W Virginia	Emergency								
Wisconsin	Full								
Wyoming	Emergency								
Dist of Col	None				Full				
Full	13	9	8	9	10	11	11	9	9
Limited	13	17	17	15	18	18	19	18	18
Emergency	17	18	19	19	16	15	15	16	14
	8	7	7	8	7	7	6	8	10

Updated: 11/13/09

Status of Adult Medicaid Dental Services, State-by-State

Alabama: No dental services for adults.

Arkansas: After much effort, Arkansas will offer an Adult Medicaid program. The program will be limited to $500.00 per year (benefit limit) with the exception of extractions and one set (lifetime) dentures or partial. Providers will be reimbursed at 95% of Delta Dental Premier 2007. Governor pulled the adult dental program-just before he signed. Budget concerns. (E-mail from Mauldin 10/13/08).

Alaska: ~~Dental services limited to relief of pain and treatment of infections associated with fillings and extractions.~~ The state will pay for minimum treatment and for preventative and restorative adult dental services. Regulations adopted under this section must include the following a maximum amount of benefits for preventative and restorative adult dental services of $1,150 for each eligible recipient in a fiscal year; and specification of the scope of coverage for preventative and restorative adult dental services.

Arizona: Dental services limited to emergencies, medically-necessary dentures, and pre-transplant services. Proposal to eliminate all adult dental care has been made.

Arkansas: Dental services are limited to treatment of life-threatening conditions.

California: Governor had proposed elimination of all dental services beginning in the 4th quarter 2003. The proposal, however, gained no momentum among lawmakers; adult services remain intact. An across-the-board

5 percent reduction appears to be likely for all providers in January 2004. Initially, the governor had proposed elimination of all dental services beginning in the 4th quarter 2003. The proposal faced legal challenges and then stalled. Then in early 2004, the governor took all specific proposals for Medicaid off the table when he proposed that the entire Medi-Cal program be redesigned. In 2005, the governor proposed a $1,000 per person/per year spending cap. An $1,800 cap was enacted, however. **(2009)Per Medi-Cal website FAQ: Will dental services rendered be reimbursable if the service was considered an emergency treatment even though the service is not considered a covered benefit?**

A: No. The dental benefit is only reimbursable if the service is indicated on the FRADS list.

Colorado: No dental services for adults.

Connecticut: Periodontia, fixed bridges, and several other services are not covered. State planned to eliminate adult care, redirecting funds to a new children's dental care model. The planned elimination of benefits for 23,000 adults was blocked on March 31, 2003, by issuance of a temporary restraining order. Dentists fervently edified their elected officials on the negative ramifications of adult cuts. The proposed service reduction has been quelled; adult services remain as they were prior to the proposed cuts, at this writing.

Delaware: No dental services for adults.

Florida: Effective July 2002, adult benefits are limited to medically necessary, emergency dental procedures to alleviate pain or infections (i.e., emergency examinations, necessary radiographs, extractions, and incision and drainage of abscesses). Governor's 2003 budget does not include any funding for dental services, but legislature may not agree and indeed may add back some adult dental services (dentures). A 2005 enactment eliminated expiration of adult Medicaid dental service program.

Georgia: Dental services are limited to emergency services such as limited examination, related x-rays, extractions, and surgical procedures related to pain, infection or trauma.

Hawaii: Dental services are limited to palliative and emergency care, including extractions, incision and drainage, some surgical services and medically necessary emergency services.

Idaho: Effective April 2002, only emergency services included for adults.

Illinois: No preventive services, or periodic exams available for adults.

Indiana: $600 cap on expenditures, effective March 2003, excludes surgical procedures and two periodontal services. Denture/partial fees were reduced by 50%. Some of the non-covered codes were effective November 2002 (same time rates for dentures and partials were reduced); other eliminated codes are dependent upon a rule change to take effect June 2003. **(Dentures added back as a covered service for adults with prior authorization – as of 9/03)**

Iowa: Effective March 2002, adult care is limited to exams, x-rays, amalgam/composites, dentures, partials, bridges, and oral surgery. Eliminated services include: crowns, posts and cores, periodontal, endodontic and orthodontic services.

Kansas: In 2006 and 2007, the Kansas Legislature extended Medicaid dental benefits to adults eligible for home and community-based services waivers for physical disability, developmental disability, head injury and frail elderly; however, 75,500 adults eligible for Medicaid remain without dental care coverage. Medicaid covers only emergency dental services for most adults, such as extraction of infected teeth, and then only for conditions that threaten the health of the person.

Kentucky: Coverage is limited, but includes oral exams, emergency visits, x-rays, extractions, fillings, for all ages. Root canal therapy, crowns, sealants and braces (for severe malocclusions) are limited to eligible recipients under age 21 meeting prior-authorization criteria. Dentures and partials are not covered. Denture repair, limited to recipients under age 21. Elimination of dental coverage is being discussed for July 2003.

Louisiana: Only dentures, denture relines and denture repairs are covered. Examination is covered, if in conjunction with denture construction. **Added extended dental services for categorically eligible pregnant women as of 2/04.**

Maine*: GAO categorized Maine adult dental care in 2000 as including "full" benefits; however, this may have been overstated, or in error. The basis benefit package remains: adults "receive selected procedures as necessary to relieve or eradicate acute pain, control bleeding, eliminate acute infection and prevent imminent tooth loss. Adult dental care procedures do not include ongoing comprehensive dental treatment, treatment of the dentition and gingiva, and routine treatment of incipient decay." Adults with "qualifying medical conditions also may receive services, including dentures. (From Section 25.04.1, MaineCare Benefits Manual).

Maryland: No emergency or other dental care included in the state-operated fee-for-service program; however about 90% of adult Medicaid beneficiaries are enrolled in the HealthChoice managed care organizations which may provide a variable degree of emergency, preventive and other dental services.

Massachusetts: Effective March 15, 2002, Massachusetts eliminated preventive and restorative services for adult MassHealth members. Adults were then covered for emergency services (includes oral surgery) and prosthetics. Also, adults having a severe disability, for example, could be designated (for three years) as "Special Circumstances" (SC) which entitles them to continue to receive preventive and restorative services. There are currently 20,000 members designated as SC. Effective January 1, 2003, adult prosthetics was eliminated for adults, except for those designated with SC, and the MassHealth Adult Dental Program became an Emergency Only Program. On April 4, 2006 – more than four years after the elimination – the House and Senate unanimously reinstated adult MassHealth dental benefits as part of the broader health reform legislation. Despite a Gubernatorial veto, the restoration of these important health benefits took effect July 1, 2006 as a result of veto overrides in both the House and Senate.

Michigan: October 1, 2003 marks a substantial cut dental services for adults, leaving only emergency services, such as exams, x-rays and extractions; this action ends non-emergency dental care for Medicaid beneficiaries 21 and over. About 600,000, including low-income mothers, destitute nursing home residents, and developmentally disabled and mentally ill people, will lose routine dental. The adult dental program reportedly cost the state about $20 million annually. Similar cuts were halted in the early 1990s by a group of dental providers in Ingham County; the county circuit court enjoined dental reductions after evidence showed potential cost increases from adults who would use hospital emergency rooms for dental care. (10/2005 Please see the attached document. **(2009) Michigan's Governor Jennifer Granholm reinstated Adult Dental Medicaid Services, retained funding for our 37county Healthy Kids Dental Program and the 800 member Donated Dental Services Program. Exec Order by governor reduces adult dental Medicaid to extractions only (eff 7/1/09)**

Minnesota: A comprehensive array of dental services is available currently. On April 8, 2003, a budget revision was introduced in the legislature to eliminate all but preventive services and dentures for adults, with a limit of up to $500/year.

Mississippi: Emergency care for the relief of pain and infection including emergency extractions, palliative care, and dental care related to treatment of an acute medical or surgical condition. Dental care for pregnant adults was reduced.

Missouri: In August 2002, a court issued a temporary injunction halting a planned reduction in adult dental services that was to begin July 2002, and would have retained only dentures and services related to dental trauma. The Governor's proposed budget for 2003 eliminates adult dental services; however, on March 18, 2003, the legislature passed emergency funding to continue the dental program, as enjoined, through 2003. Signed into law April 2005, S 539 eliminates adult dental services in Medicaid.

Montana: Beginning February 2003, dental service for adults was reduced to emergency dental services only. This reduction, which affected 70,000 adults, was a temporary measure that was reversed in 2003. Although the adult dental program has been restored **(with some limitations)** effective July 1, 2003, it is anticipated that inadequate funding will lead to significant reductions to the adult program at some point during the coming biennium if the number of adults eligible for Medicaid services remains at the present high level.

Nebraska: Adult coverage is fairly comprehensive and covers routine examinations and prophylaxis yearly, preventive services (fluoride, x-rays, sealants) restorations, extractions, endodontics, dentures (complete and partials), periodontal services, and crowns for anterior and endodontically treated posterior teeth. Orthodontic services are not covered. In the fall 2002, the Nebraska legislature passed a bill that ended Medicaid eligibility, including dental services, for 25,350 clients (12,750 adults and 12,600 children). In January 2003, legislation was proposed to reduce the adult benefit to emergency services only. In conjunction with state dentists' urgings,

the legislature's Health and Human Services Committee, however, sent the bill forward without the provision to eliminate the adult program, and the appropriations committee left money for the program in the Medicaid budget. If the adult program was eliminated it would impact 28,000 adults.

Nevada: Emergency services were limited further in February '02 to include only "palliative care," defined as treatment to control pain, bleeding and infection. Covered services include limited evaluations, x-rays, sedative and temporary restorations, extractions, and fillings/crowns only for abutment teeth for existing partial dentures, and related services.

New Hampshire: Dental emergency services, including extractions, and medically necessary treatments for trauma are covered.

New Jersey: A wide range of dental services were saved through an all-out defense program. The New Jersey Dental Association expended a great amount of resources to defend adult dental services in Medicaid. The governor proposed to eliminate adult dental Medicaid early in 2003. Dentists had to educate lawmakers about the value of oral care, and its relationship to overall health.

New Mexico: Services in all categories are available, but endodontics, sealants, and topical fluoride are not generally covered for adults.

New York: A wide range of dental services are available.

North Carolina: Covered services generally are comprehensive, but preventive services are not available for adults. In 2003, the state has proposed elimination of adult dental services, but the legislature is proposing a different set of cuts, such as elimination of services for the medically needy population. As of this writing, there have been no reductions to dental services in Medicaid.

North Dakota: Medicaid covers exams, x-rays, cleaning, fillings, surgery, extractions, crowns, root canals, dentures (partial and full) and anesthesia. A proposal to eliminate dental services for adults was made, but in the last weeks, the legislature restored basic adult services for the 2003-2005 biennium. Final decisions may not be made until the end of April, 2003**. Additional coverage of anterior crowns necessary where endodontics has occurred with prior approval, posterior teeth limited to SS crowns, partial dentures can now include anterior teeth with prior approval, all added as of 10/03.**

Ohio: A fairly comprehensive array of services is offered to adults, although topical fluorides and sealants are not available, and periodontal services are restricted. In 2003, the governor proposed to discontinue dental and other optional services in Medicaid order to curb state spending growth. If not for the full dedication of Ohio dentists to educate lawmakers of the residual costs that result from dental cuts, adult services would have been eliminated. The effort from the dental community resulted in the continuation of adult dental services. *10/2005 H 66 instructs Medicaid director to reduce dental by rules; does not make specific cuts.

Oklahoma: Dental coverage for adults was limited to emergency extractions and reconstructive surgery when medically necessary; however, these emergency dental services were eliminated, effective October 2002. Under SoonerCare Plus, some Medicaid enrollees had some dental benefits; these were eliminated in January 2003. **Coverage added back for emergency extractions as of 10/03**.

Oregon: A substantial array of services is covered in the "Oregon Health Plan Plus," with some limits**.** There is a $3 copayment for restorative, but not diagnostic dental services. Effective March 2003, however, dental services for all "Oregon Health Plan Standard" beneficiaries (adults and children) are eliminated. **Oregon restored of some prior benefits that had been cut. Emergency dental, and some medical equipment will be part of the standard package. The changes affect only the 50,000 people on the standard plan, not the 300,000 people on the plus plan.**

Pennsylvania: Dental coverage is comprehensive.

Rhode Island: Dental coverage for adults is limited in the areas of endodontics, fixed prosthodontics, and orthodontics.

South Carolina: Adult coverage is limited to emergency services.

South Dakota: Covers exams, X-rays, cleanings, fillings, and provides limited coverage for endodontics, crowns, partial dentures, complete dentures and anesthesia.

Tennessee: Adult coverage is limited to emergency services.

Texas: No coverage for adults, except for dental services which are provided by a dentist who is functioning as a physician, and then only for services that are secondary to a life-threatening medical problem.

Utah: Effective June 2002, adult dental services were limited to emergency examinations, x-rays and extractions for the relief of pain and infection. A 2005 enactment states the legislative intent is to restore Medicaid adult dental services. A spokesman for Gov. Jon Huntsman Jr. (R) called the restoration of funding one of the governor's chief health care priorities.

Vermont: Services include emergency dental care for relief of pain, bleeding and infection, selected preventive and restorative procedures rendered to limit disease progression, and necessary diagnostic and consultative services. Services not covered include sealants, periodontal surgery, comprehensive periodontal care, orthodontia and prosthodontics, however the denture benefit was eliminated September 2002. There is an annual benefit maximum of $475 per person.

Virginia:** GAO categorized Virginia adult dental care in 2000 as including "partial" benefits; however, this may have been overstated or in error. Virginia covers dental services only when the service is covered under Medicare; Medicare specifically excludes services connected with the dentition or structures supporting the dentition. Emergency dental services are not covered. Dental services related to an underlying medical condition may be covered.

Washington: In July 2003 the state eliminated most dental benefits, maintaining partial dentures and preventive services. The Washington State Medicaid program sent a letter to the state's dental providers and stakeholders, requesting feedback on a restructured adult dental program that fits new operating budget for the 2003-05 biennium. FYI, the Washington program reverted to full coverage for 2007-08, but is threatened in the coming 09-10 biennium (as per Hemion e-mail 10/10/08).
West Virginia: Dental coverage is limited to emergency services only, i.e., emergency examination and associated x-rays, along with incision and drainage, or extractions**.**

Wisconsin: The state currently has comprehensive dental services.

Wyoming: Coverage is available for emergency relief of pain and/or infections and includes limited oral evaluation, palliative treatment, extractions, and excision and drainage.

District of Columbia: The FY 2007 proposed budget provides $1.7 million in local funding to provide some dental services to adults. This is the first time adult dental coverage has been provided by Medicaid in the District. Adults on Medicaid will be eligible to receive a comprehensive dental benefit, which preliminarily includes: Exams every 6 months, cleaning and fluoride treatment every 6 months, fillings, x-rays, and dentures (limited to one-set every 5 years). Crowns were excluded because of cost but can possibly be added at a later date. This benefit will be FFS – the current MCO benefit will be carved out and become fee for service. At this writing (1/4/07) the proposal is currently at the Mayor' office for signature and then has to be approved by CMS. It will mostly likely be up and running around March of 2007.

Appendix D: Compendium of Comments in Response to Open-Ended Question

Category #1 of 9: Lack of Funding (41 comments)

8 We are very concerned about we are hearing about Dental needs for people with special needs such as our Son... What will be his Future... what will happen concerning his Dental care when we are not here to help him... as we have health issues as well and don't know what the future holds... Very concerned about only our Sons Future, Very!!!

35 Go twice a year and have relatively good teeth and care, but will not be able to afford dental

43 Client grinds teeth which has caused some tooth loss, she also has no extra money to pay for any routine dental care.

44 I recently paid for some private coverage, but before that it had been several years . . . I've developed some problems from leaving stuff unattended. In a perfect world, maybe I should have gotten braces as well, but I think it's a cosmetic thing. I will just be satisfied to have a healthy moth.

46 My parents have me on their dental plan. It only covers basiccleanings, no endodontic care. preventative care once my insurance cuts off

51 All my teeth need to be extracted due to severe decay but I have no funds to do so and I am in constant pain.

56 Dental work is expensive

67 It is a strain on our budget but as his mother, I do all I can to have his teeth cared for.

84 Can afford to see dentist for cleaning but not to have major work done. For example, I need crowns on several of my teeth but cannot afford work.

106 It's not right that we get no help with dental, our teeth still need attention. Just because we became 21 years old, that doesn't mean that I don't get any more cavities. I cannot afford dental costs with what I get from SSI.

197 I do not have enough money for dental care. My family pays for me. It is very expensive. I needed a crown for a broken tooth and it cost more than $900. Please help.

198 It is very expensive to have my teeth cleaned because due to my disability I must have general anesthesia. AHCCCS does not cover dental expenses for 21 year old or older people. My mother takes me to Los Algodones, Mexico, to have this procedure. Even then, it costs $700 just to have my teeth cleaned. Since my SSI is $679 a month and I pay $600 in rent, I must save for almost two years to have my teeth cleaned. I hope that AHCCCS starts covering this expense for people like me.

176 Right now I am very fortunate to find a Dentist, Dr. Zuniga who is doing the best he can for my teeth for no money. He has wired some of my teeth together so I may eat because I cannot afford anything else. He does surface cleaning, because I cannot afford deep root or replacement of my teeth. I would have to be put to sleep for anyone else to do the work I need but cannot afford. Thank you for listening.

177 I was getting dental fillings at California, but due to cuts on medical I'm no longer eligible to continue my dental work and my teeth need a lot more work.

S10 I must go to the dentist every six months for cleaning my teeth, but I have to pay. I have autism and teeth problems. I need insurance to pay for all kinds of dental problems. Cerebral Palsy, Mental Retardation, no speaking.

247 Because of severe Cerebral Palsy, I need total care. Whenever anything is put in my mouth, I bite it. My teeth are worn down from grinding, which I cannot control. Since I need to be sedated when going to the dentist, it is very costly. (About $3000 to $4000 every time I go. My parents had to cash their IRA to pay for my dental care.

250 AHCCCS discontinued at 21 - NEED dental insurance to continue into adulthood.

262 I had regular checkups with the dentist before I turned 21. Then my coverage ended.

269 I wish there was a dental plan for DD people

142 I used to see a dentist regularly for nearly 15 years until I moved to Casa Grande, AZ. I did go a few times to Sun Life Family Clinic until I could no longer afford the copay. I have Medicare, not AHCCCS.

159 I am now receiving health care from Medicare. I plan on signing up for dental services from their plan when I can. Right now I can't afford it.

213 If I had dental insurance, I would use it.

329 My family has paid for my dental work for the past 2 years, but due to lack of work, and the economy, they are going to be unable to continue

331 I now have dental care through Medicare/united health care. The people on AHCCCS should have dental insurance as well. I benefitted from the $1000 dental plan AHCCCS offered years ago. I wish they would bring it back for the members. Thank you.

333 I want to have dental coverage so I can see my regular dentist before age 21. He knows how to handle me and knows me. Right now I'm thinking very hard how I'm going to handle my teeth pain. The only thing my insurance covers is emergency teeth pull. I'm really thinking for my daughter. This is coming from Mom.

449 I am young, but need regular care that I don't get because of cost. I would pay for a copay if I had coverage so I could get yearly checkups and cleaning.

315 I need dental care to clean my teeth and just to keep up with my teeth. We don't have dental care with SSI. We need one.

316 I need free dental cleans yearly. I have no insurance. I would go if I had insurance

318 The insurance stopped.

393 This client Social Security payment of $698 of which $614 is used for room and board, leaves only $84 a month for all other needs. Has no dental insurance or other coverage for dental care. As she can manage she does cleaning and minor repairs as she has no other source of money.

412 The high cost of dental care! My daughter needs to now have teeth pulled and a set of dentures. The cost estimate was over $14,000. We have not been able to care for her dental and have considered placing her outside the home because of this need. We worked for over 10 years trying to pay for dentures.

416 Dental care is very expensive and AHCCCS will not cover and private insurance has high deductibles and I cannot afford it. Please cover my deductibles so I can have much needed dental care.

365 He needs his dentures aligned and I don't have the money to fix them. Thank you. Signed by Mother

351 Paying for anesthesia out of pocket is expensive.

358 I wish he could go but when he turned 22 the assistance ended.

382 I understand that my insurance doesn't cover after the age of 21.

341 It takes many months for me to save enough to see a dentist. I also have glasses and must see the eye doctor, which is not paid for and no insurance helps. My pay is very low

388 Many disabled people receiving ALTCS do not get any dental care.

280 Future dental care will need to refer to Phoenix Indian Medical Center.

307 She is in need of a company like Clear Choice and the AHCCCS program should pay for it. It is not to look better, it is so that she can eat better without problems.

232 Went to dentist over 20 years ago in the Army.

Category #2 of 9: Sedation Required (35 comments)

12 Currently this person needs IV sedation for any dental work. This cost makes it difficult for this person to see the dentist. Many of our clients are in the same position.

22 I need to have anesthesia for dental procedures, could not find a dentist who works with adults, had to pay over $1,800.00 to have my teeth cleaned. Currently making payments.

48 I must be put under for dental work so it is all done at once

57 I must be sedated, which is extremely expensive

58 Adult needs to be put completely to sleep. This is very expensive for family plus need to see an out of town doctor. Doctors don't like to put patients to sleep too often. So we go every 2 years.

55 For some fillings I need general anesthesia due to involuntary movement of head and neck.

74 Because of the need for anesthesia, I couldn't go back [to the dentist],and he didn't take anyone over 18.

85 Require sedated dental work.

187 Need to be sedated.

203 Because of my disability [issues] (autism), I need to be anaesthetized and intubated. This increases risks, but I am unable to understand why I must sit in the chair, keep my mouth open, understand and complete requests by dentist, etc.

214 I need to be sedated for any kind of work that is to be done on my teeth. No money to go to the dentist. It is too expensive for me. The state will not provide dental care for me. I am over 21 years.

228 Need full anesthesia to have word done, such as fillings.

229 I am my daughter's parent/guardian and dad. No funds through AHCCCS / long term care. We pay for her dental on credit card from September 2010 to now. Each time we go she needs anesthesia. 1st time $2300. 2nd 3200. At least 8 teeth pulled I've asked AHCCCS to help with this they said no funds.

222 I'm a 22 year old Down Syndrome very low functioning. I need to be medicated and sedated for dental care.

274 [Name of provider] did not have a doctor available that could do the procedure of cleaning and checking teeth between 2008 and 2010. There was always a new dentist when we went and they didn't do anything except try to check the teeth without x-rays or thorough check. It was always "come back later." The new dentist had

problems with the anesthesia. I had to go to ICU for congestive heart failure due to anesthesia. Please, isn't there something, some way safer than general anesthesia? Congestive heart failure due to anesthesia is a scary, scary situation. New dentists every time you go to a clinic is also very frustrating and uneasy.

275 I need sedation for dentist. Dentist I go to is 40 miles from my home, and I must be restrained. I cannot afford IV sedation for dental work. The dental clinic I attend is closing in December 2011. I don't know what I will do about a dentist then. I grind my teeth and very front teeth are worn down to the gum, and it's becoming more uncomfortable for me. I have one crown that has cost several hundred dollars, and I can't afford more.

276 When I need tooth extraction, I need to be sedated, and this is very costly. My family cannot afford this without dental insurance. I missed my dental cleaning because my father lost his job / dental insurance. I waited for a year until our family could obtain new dental insurance.

265 I answered these questions on behalf of my disabled daughter. She has an incredible fear of dentist and has to be anesthetized for dental visits. It is extremely traumatic. We have no dental insurance and can't afford it, especially under her circumstances. Therefore, we don't go to a dentist anymore.

285 Sees Special Needs dentist 6 months. Dentist's covered by United Healthcare. Will not use IV sedation. His IV sedation is given by an anesthesiologist. He cannot even be examined w/o sedation. Oral anesthesia does not work. Family pays for dental work from a special needs trust. Dollars from trust will not last forever.

245 I am a special needs man, with many disabilities, and due to insurance not covering outpatient anesthesia, it costs too much for me to have cleaning procedure I need twice a year.

295 Waiting on dental care because I cannot afford general anesthesia. Currently have problems with choking because of difficulty swallowing. Cannot chew food very well because only have a few teeth left. Group home staff does not do an adequate job brushing client's teeth. I would love to be able to set up an incentive program for staff if consumers have a good check-up because they really don't care about consumers' teeth.

296 Dental treatments are expensive and my only income is SS Disability - my disability was cause by instrument damage to my head when forceps were used for my delivery.

337 Anesthesia fees are necessary but may or may not be covered at every visit to my dentist. Dental care is a necessity for preventing major health complications. The biggest obstacle that we have encountered as a family is the unwillingness of the insurance companies to cover the special needs of disabled adults living at home. As parents of a special needs child we have fought hard to provide the best care we can find. As [our child is] an adult now, the job has turned even harder. The unwillingness of the state to help parents with children living at home and their dental care needs is in my opinion a discriminatory policy. Luckily, we have found advocates in Dr. Anthony Caputo and Dr. Michael Mayo that have shown my child respect, concern for his dental health and a strong desire to help us and other caregivers to do the best we can for our children.

300 Unable to perform any dental care including regular check-up without sedation.

452 Having severe problems with wisdom teeth coming in. Oral surgeon refuses to take them out in the office, suggesting we wait until they are impacted and must be removed. Gompers Dentistry will not accept new patients, and other dentists will not take her, due to her mental handicap. She is extremely afraid of the dentist which makes it impossible to examine or clean without strong restraints or putting her out.

453 Went to dentist for checkup, needed cleaning and was told I need to remove my 4 wisdom teeth. Need to go to a surgeon. Went to surgeon. It's over $2,000. Need to be sedated. Don't have the money, so I'm waiting.

455 I have to be strapped down or put to sleep.

292 My son is trying his Medicare special needs HMO Dental plan. The dentist will do preventive and small(ish) jobs there. For any large jobs, we will take him to the sedation dentist he has seen in the past. The two offices have agreed to coordinate and the out of plan sedation dentist will offer discounts.

346 I have special needs and am non-verbal. I am frightened of the dentist and need full IV sedation for dental work, which costs more than a thousand dollars per visit, even at the “low-cost” providers. I have AHCCCS, but not family to assist in the cost of dental care, so my dental care takes up all of my available funds after I pay room and board and then some. It is difficult for me to eat because I am missing teeth, and without proper dental care, I fear I will lose the rest and the ability to each regular foods on my own.

456 Dental work is very limited under the State program. My son has severe behavioral issues due to his fears. Therefore he must be put under to have regular dental visits. He is a very difficult time for all involved. I do wish there was an easier way to get him checked out. Especially since his behaviors and his extra-large size.

435 Must be put out [sedated] for any and all work, so it’s pre-scheduled.

414 I would go to the dentist more regularly with insurance coverage. I could not find a specialist that had facilities to use anesthesia for a root canal. I have to be asleep due to tremors and movement.

415 I am severely mentally retarded, and do not understand what is happening. I become very frightened. Due to uncontrollable movement of my tongue, brushing teeth and routine dental care is difficult to perform. I require IV sedation in order to have work done on my teeth. The cost of this is beyond my means as I only receive SSI benefits.

394 I have cavities that need filling, cleaning and gum issues. I have seizures and dentists won’t work on my teeth without putting me to sleep because of that and not being able to hold still.

305 I have Prader-Willi Syndrome, I do not swallow good so I keep saliva in my mouth all the time. I drool I try my best to use a Kleenex. I am not always successful.

Category #3 of 9: Specified Treatment and Needs for Oral HealthCare (20 comments)

290 She did have her wisdom teeth and 12-year molars removed about 12 years ago because her mouth is very small. I checked the box that says she has all her teeth she does have all the teeth that fit in her mouth.

172 Had teeth pulled on last visit to dentist.

294 I refused dental care through AHCCCS because all they do is pull them. They wait until the dental problems are so bad, that they actually told me that I couldn’t get braces on my teeth till I lost at least 20 pounds due to not being able to eat, being very underweight, I couldn’t afford to lose any weight. I feel that their reasoning is that because we are disabled, it doesn’t matter what we look like or being able to eat. So OUR dental needs are NOT important

200 I wear dentures, but the teeth fell out, they don’t do a good job.

220 I need my last three teeth pulled out.

425 Autism, biting, clenching, grinding

426 I’m in need of implants as my jaw is irregularly shaped not your typical jaw for dentures.

238 I need to get the rest pulled and a set of dentures.

308 The cap broke off my tooth part of the tooth also broke off.

314 He needs all of his wisdom teeth out. They are infected. This process is expensive. So we are trying to get a loan to pay for my son’s part of the bill.

347 Due to my disability, my gums are deteriorating quickly, and the enamel on my teeth is almost completely gone. I have missing teeth and many silver crowns. I worry about what will happen to the rest of my teeth when my dental insurance goes away at age 22. My family cannot afford dental care.

431 The first visit for cleaning was put in garment to hold hands down. Daughter cried and fought. The dentist could not finish afterwards. Patient bit through her lip: every visit to the dentist she gets agitated and bites her lips. A family doctor wrote a prescription for her to have anesthesia for any dental work done. She now has scarring below and above her mouth from biting herself. She is non-verbal, so we watch her actions: grinding, biting hitting, gagging at mouth gum bleeds some times.

1 I have been recommended to have four cleanings a year

433 Chews on things, thus having 4 front teeth (upper) bonded - James is compulsive about chewing may need to be bonded again. Night time grinding.

366 I am scheduled for appointment for dental treatment and routine examination annually.

368 Had wisdom teeth extracted.

410 I had fractured tooth and extracted. Need work but this is beyond my income. Very expensive but necessary.

418 Need bridges again; have no money to get some. Probably need teeth to be pulled due to cavities. Have a dentist that helps mentally challenged people.

395 Has not been to the dentist in over 15 years. I saved enough money to take him. He needed a root canal, deep cleaning of entire mouth, x-rays, but there weren't any cavities. I am his sister and caregiver, and he lives with me.

379 I know I need a lot done to my mouth but I do not have the money to get it taken care of because of my accidents I have broken teeth that need to come out cause it is causing infections and sores so I would like to get it taken care of.

Category #4 of 9: Family Dental Coverage or Private Pay (18 comments)

29 My mom will be 68 this year and will be retiring soon. When she does, neither of us will have dental insurance coverage.

45 2 years ago I was referred to a special needs dentist in Phoenix, had wisdom teeth removed, 1 capping; all teeth sealed. Cost was $7700. I was under anesthesia for 6 hrs. Parents paid entire bill.

217 My son needs to see a dentist at least twice a year for cleaning. He has very sensitive teeth and gums so it is difficult to brush his teeth.

223 I pay for her dental work now. She doesn't feel pain, so we have to watch her very closely. If she gets hurt she will not say anything.

224 We have private dental insurance on daughter thru my employment in addition to the DDD insurance. It is difficult to care for her teeth as she has a history of biting and seizures. Still paying on second appointment. Last appointment, June 25, 2011. She eaters no sweets or soda. Healthy diet. It's her meds that make her teeth unhealthy, but she needs her med.

252 At this time, I am still eligible for coverage under my father's dental plan. This benefit will end upon his retirement in 2012 and I will then have to self-pay.

257 The only reason I have any dental care as someone with ALTCS and AHCCCS is because the foster family who raised me continues to pay for any dental care we receive, including cleanings, fillings, etc. as well as a sonic toothbrush. They are now my legal guardians. Everyone should be entitled to routine preventive care to reduce emergency care needs.

282 My teeth look pretty good but in fact they are not good. I've had a fortune in dental work done and most often paid by parents. I've had several at least 4 or 5 root canals, wisdom teeth surgically extracted, probably the same number of crowns and many fillings and re-fillings.

335 Mom has strong feelings on the importance of dental care goes every 6 months for cleaning and check-up. Has dental insurance under mom's dental at work, only due to the fact of it being low-cost. Would not have private dental if it was too expensive.

309 She sees a dentist yearly through my personal insurance and her AHCCCS is her second.

401 Parents have to pay big money to have any dental work done on individual with special needs, but they do it because it is important.

438 On my mother's insurance

409 It is contingent on my parents to pay out of pocket for this service.

392 I am an incapacitated adult in a wheelchair. I visit my dentist 4 or more times per year to save all the teeth I have for eating. I have been on medications for seizures, which affect my gums and dental health. I always have to pay out-of-pocket expenses each time I visit the dentist. My guardian and family member pays the dentist.

389 Has had pain because of no dental coverage. I put him on my insurance. Still [costs] a lot of money we don't have. I think you could have come up with programs for adults. Your planning council don't care about his pain. We're on a fixed income and to pay a dentist is very costly. Signed by Grandmother and Guardian.

380 I pay for all dental care I receive with funds of my own.

381 We are very dedicated to our son's dental care. Most of the cost comes out of our pocket since he can't afford it. Regular cleaning appointments twice a year cost us $500-600! Doctor care and prevention are critical to daily living and general health.

Category #5 of 9: Special Needs Dentistry (17 comments)

69 It's very difficult to find a right dentist for dealing with the people with special needs.

117 I have had bad experiences in the past with dentists who didn't understand needs and issues related to my disability, and weren't patient and caring.

119 I had a tooth that was very sensitive. I could not explain where my pain was and my mother thought that I was having abdominal pain. The dentist placed a layer of dental cavity material on the top of my tooth which relieved the pain

363 The first Mercy Care dentist I ever visited I had to leave before any work [was performed] because an instrument fell on the floor. He picked it up and put it on the tray!!! I have never gone back to a Mercy Care dentist!

S3 Need to see a dentist who is familiar with special needs patients. Last visit, dentist was not very caring, and our daughter was gasping for air and her heart was beating very fast; we think she would've had heart failure.

439 My child has been to a special needs dental clinic. They were negative and shame-based, They complained about her being unable to sit still and adverse reactions to being touched (Autism). Went by

recommendation to a private dentist who was gentle and understanding. He made referral to have wisdom teeth removed with sedation. He then retired. Child is in need to have braces to prevent loss of front teeth, but this is not covered under AHCCS / long-term care. Would be nice if services were covered on a case by case basis (need) and sedation for prevention such as cleaning were covered. My child also has two cavities at last check up. They cannot be treated without sedation. We cannot afford it. [She]Complains of mouth pain, and we are at a loss to get treated. Worry about loss of teeth, especially protruding front teeth and gum disease. Dentists need more compassion and education about the DD population.

76 My dentist says i need to come in every three months for a cleaning because i have gum disease. The Dentist has a flat body shaped board with big flaps off to the side that pull over me and Velcro my body to the board. They call it a papoose thing. So I am only able to move my head when i feel pain during the cleaning. My Mom kind of holds me too. We need to find another dentist for me. This one is just so expensive. He charges anywhere from $25-$100 for behavior fee, depending how much I move. It's been $100 extra just for that .It's been over $300.00 for my cleanings the last several months. He said things have gone up. I'll say. So for me to continue to see this doctor, it cost me $100.00 a month to accumulate the $300.00 for my appointment. I have tried other dentists. Not good results. Thank you. Signed by consumer, as completed by mother of consumer.

80 I need AHCCCS dental care. The Syndrome I have is Velo-Cardio-Facial Syndrome (VCFS), and because of it I do not have room in my mouth for all my teeth. They crowd together are very hard to keep healthy. I had braces about 8 years ago, but they didn't help. My mouth is too small for my teeth.

180 Attends Gompers Dental Clinic at this time and an outside provider for periodontal issues.

266 It is difficult to find a dentist in our area that is in AHCCCS and will see a person with special needs. We usually take him during the Special Olympics state games. The last dentist we saw in this area screwed up the billing to AHCCCS and we ended up paying several hundred dollars out of pocket. Can't afford to let that happen again.

423 My son goes to a wonderful, caring dentist who is familiar with issues with special needs adults.

277 Robin went to a dentist for years but he was only for younger patients. We haven't found another dentist that will take special needs adults. I would appreciate any help in getting a dentist near Sun City. I do not drive.

427 Need to find a dentist that will work with the Disabilities. Hard to find.

391 It's been hard to find a dentist who will take me as a patient. Due to my special needs, and also the cost has not helped any.

311 [Named clinic] is a very nice place for people with disabilities.

326 A list possibly for dentist familiar with special needs adult that have had a bad experience and are afraid and know the needs of special needs people.

349 I enjoy seeing my dentist. He is a good guy.

Category #6 of 9: Obstacles to Care (16 comments)

297 In the past, dental work came through AHCCCS had only been available intermittently. It cannot be relied on to be there when needed. [It is located] in metropolitan area, and can't be easily accessed from rural areas. Phoenix is a 5-hour drive from my home.

302 Not enough doctors available for special needs patients! Only 3x in 23 years. 1st just looked, said to clean have to strap down. 2nd - did strap down, awful experience. 3rd under sedation to clean and pull 2 teeth.

450 I am waiting for referral to go through.

454 Waiting is behavioral issue. Leaving can be another behavioral issue. If sedated need at least 2 caregivers to assist.

375 Rosario is mentally challenged. Cannot do or understand oral directions and will not be able to physically follow or understand anyone. She is blind, deaf, and cannot sit still for any amount of time. And will not take too well to being restrained for any more information feel free to call me.

442 I haven't had good knowledge about dentist much because my family had English (language) problems.

2 Was never made aware that she had dental coverage.

305 I have Prader-Willi Syndrome, I do not swallow good so I keep saliva in my mouth all the time. I drool I try my best to use a Kleenex. I am not always successful.

306 Does not like to have her teeth brushed at all. Constantly chews.

293 Our son became very frightened of dentist and so we have not taken him for approximately 7 years. We plan to go; we check his teeth regularly and when he receives a haircut (at home) my husband uses an ultrasonic toothbrush and looks carefully. Now that our son has completed high school one of our goal is to have a check-up and a cleaning. We are deeply appreciative of his having APIPA.

303 Coverage for as often as needed to go to dentist, needs every 3 months, not just 6 months. Doesn't want caregiver to brush teeth, wants to be independent, but is not able to do a proficient job.

334 Grinding teeth a real problem.

272 Being in the hospital, don't know when to be coming home.

273 I was born missing 18 teeth.

186 AHCCCS Dental is very bad.

403 Canker sores all over mouth

Category #7 of 9: Frequency of Cleaning (13 comments)

1 Because of swallowing difficulties since birth I have not been able to control this and panicked each time I had a cleaning on the 6 month schedule. This resulted in plaque being swallowed into my lungs and my developing aspiration pneumonia which fortunately responded to antibiotics. After this situation I went on a monthly cleaning so that the process was less traumatic and eventually even enjoyable. Now, as a monthly cleaning patient, they enjoy my visit and so do I.

3 My son doesn't take anything by mouth and he's a mouth breather. The combination of the two conditions means that he builds more plaque than usual. The plaque causes gums to recede and become oversensitive. The thing saving his teeth right now is the care he gets at his particular group home. As a general rule dental care is the one thing most lacking in disabled children and adults. My son has a bite reflex and is unable to release at will. He has to be put to sleep. It costs a minimum of $130.

7 My teeth and gums are in poor condition and I need cleanings 3-4 times per year. I also need about 6 root canals and crowns right now.

88 I go for cleaning and check up every 6 months, I have been cavity free.

124 In order to keep my teeth and gums in good condition I need to see my dentist at least every 6 months. Dental care on a regular basis is a must for everyone and it should not depend on whether or not you are developmentally delayed or not.

190 Need to see a dentist for checkup. Over 15 years since I've been to a dentist.

201 Doesn't go to dentist regularly because parent cannot afford to pay out that kind of money. They (mom and son) are on a limited income. Consumer needs to follow up with more gum treatments or lose teeth. His handicap will not work with dentures. Not able to cope.

219 She has had difficulty keeping her teeth clean since she was little. She is now 23. I help her, but it is a challenge brushing her teeth, as she moves around, doesn't like it. At every dental check-up (every 6 months) she has plaque build-up and cavities, and they always tell her to try harder.

234 My teeth are in good condition due to twice yearly dentist visits for the past 45 years.

270 I form plaque on my teeth easily and require cleaning frequently (more than 3x per year) per the dentist that cleaned my teeth the last time.

287 Brushing teeth is difficult. He does not open his mouth wide enough to really brush them well. But everything considered, his teeth are in pretty good shape.

185 Family has always made sure he had good dental care.

383 Go consistently, every 6 months for cleaning, x-rays and self-pay.

Category #8 of 9: Relationship of Dental Hygiene to Overall Health (12 comments)

181 It is wrong not to offer dental care for adults with disabilities. Poor dental care contributes to other health problems.

215 Due to non-coverage, this group of individuals does not receive the care needed, causing increased risk of infection, septic, and the lack of ability to eat.

444 No dental insurance is an emergency home visit waiting to happen. Everyone knows good dental hygiene is essential for EVERYONE. Please get dental coverage back for adults with Developmental Disabilities! Thanks.

445 I believe people with especially special needs with low income should be provided dental care. Preventive being most important before there are major issues. Certain mouth infections can kill you.

350 My son needs assistance soon to have his mouth looked at because I want him to be able to chew his food and not just swallow everything that goes into his mouth. I have a fear he might choke one day. I hope you can put yourselves in his place. See you are able to go to a dentist or pharmacy to take care of yourselves or your loved ones, but my son or any brain-damaged individual is unable to. HIs last visit resulted in having six teeth removed. Some were under the gum line or on the nerve (exposed) and most were black from infection. Put yourselves in his place, please. Signed, Mother/Guardian

304 Please consider the fact that a lot of these adults have been / are on meds that cause decay. It's not that they are negligent of their teeth, but is something beyond their control. With regular preventive care they would be able to catch it before it got to needing a root canal. Just because they are adults doesn't mean they don't need dental care. If anything, these adults need it more than typical adults. With the financial burden now placed on the families, even more dental care will be bypassed.

299 You have so many questions about dental, but not health. Why don't you care about health? Also, you ask so many questions yet there is no help for dental insurance and care. It all comes out of my pocket for dental, and all you want to do is pull teeth!

385 Dental health is just as important as mental or physical health. Ask any doctor!

196 I am thirty-one and never had a cavity other than the crooked teeth I have good oral health. I never got braces because Mom didn't think I could tolerate them!

421 I have been really struggling to get my son's dental work. Last time he was able to go was 4-5 years ago when it was briefly covered at the AZ School of Dentistry. They were unable to start an IV there. He was trying to get up and has hard-to-reach veins . . . they sent him to an outpatient surgery clinic and he was sedated before arrival. He is in daily pain, but I'm unable to pay for those expensive procedures. Also, he has a very large tongue (Down Syndrome and small palate). I can't even see his lower teeth to brush them properly. I just guess where they are and use an electric brush. He has a strong gag reflex and vomits easily sometimes when brushing (or attempting). AZ School of Dentistry doesn't want to attempt treatment now because of prior difficulties. He's also terrified of dentists (and doctors) and IVs. He has deformed and missing teeth (born without many). I'm afraid he'll lose what few he has if I don't do something soon. It's very bad for him to have this chronic infection in his mouth, as it could spread to his heart and cause myocarditis. People with disabilities are in desperate need for free or reduced services. Note: On front of survey: ""I am very pleased to receive this survey. There is a TREMENDOUS need for dental services for disabled people. Thanks! It gives us hope!

359 I am a mother and the sole caregiver of all my son's needs. Twenty-one years of trying to take care of his dental the best I could. Even making sure it was a part of his IEP when he was in school. Children on up to adults with deep health problems and problems that may or may not be avoided no matter how well they have been taken care of! Not to mention the physical body pain without having added dental problems and pain to go with it.

325 Dental care is vital. Client has had many issues - medical issues that all directly related to poor dental hygiene.

Category #9 of 9: Medication Issues (9 comments)

47 Most of my teeth [have] caps or bridges. I only was able to get them done because my sister paid for it. I suffered headaches, and mouth pain for years. I take medicine for seizures, and that medicine affects the health of my gums. I didn't get preventative dental care for years because I was poor and couldn't afford it. Had I had that preventative care, I might have prevented much of my dental work from having to be done.

28 Need additional support from family members for flossing. Would like to get teeth whitened due to stains from medications

24 want to make sure i have my teeth for a life time. I want to make sure I am aware of life threating of my teeth, gums, or losing my teeth.

28 Need additional support from family members for flossing. Would like to get teeth whitened due to stains from medications.

149 My medication causes tooth decay

34 I have a latex allergy and I also take an antibiotic (Amoxicillin) before a dental visit due to my shunts.

317 My teeth and gums are in bad shape because of medication. I was on Dilatin [anti-convulsant], I have two sets on the bottom. I do not talk, so no one knows if I have pain. I need the help I've been getting.

356 I take anti-seizure medication which causes gingival inflammation.

399 I need regular cleanings. I take medication that yellows my teeth. Caregivers are lax with overseeing my help needed for regular brushing or flossing. No one on staff enforces hygiene for my teeth. I would like to have nicer teeth and realize this depends on staff assistance.