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Oral Health Resource Guide.

A.T. STILL UNIVERSITY
FIRST IN WHOLE PERSON HEALTHCARE

ATSU

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The mission of the Arizona Developmental Disabilities Planning Council is to develop and support capacity building and systemic change that increases inclusion and involvement of persons with developmental disabilities in their communities through self-determination, independence and dignity in all aspects of life.

The A.T. Still University of Health Sciences-Arizona School of Dentistry and Oral Health (ATSU-ASDOH) wishes to thank the following members of the Oral Health Resource Guide for their expertise and support in the development of these materials:

Jack Dillenberg, D.D.S., M.P.H, Dean, ATSU-ASDOH

Maureen Romer, D.D.S., M.P.A., Associate Dean, Post-Doctoral Education, Director, Special Care Dentistry, ATSU-ASDOH

Denise Frances D.M.D., FAAPD, Associate Director Special Care Dentistry, Faculty Advanced Education in General Dentistry, ATSU-ASDOH

Rebecca Schaffer, DD.S., F.A.A.P.D., Faculty Special Care Dentistry, Advanced Education in General Dentistry, ATSU-ASDOH

Sarah Usher, M.P.H., D.M.D. Candidate ASDOH 2014

The funding for this project supports, in part, the development of an Oral Health Resource Guide for persons with developmental disabilities. This resource guide is in direct response to the Arizona Developmental Disabilities Planning Council's goal to "Empower persons with developmental disabilities, their families, and others who support them by linking them to information that promotes informed decision making about their choices and their quality of life."

This guide should be used as an information resource only.



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INTRODUCTION

Persons with developmental disabilities are at particular risk for dental disease. Prevention of dental disease is the best answer for these problems.

Prevention is the #1 priority

This aim of this oral health resource guide is to provide up to date online dental information compiled from multiple resources to help persons with developmental disabilities and their caregivers become educated about oral healthcare, in order to help them prevent dental disease. It also hopes to serve as a resource for obtaining dental care to avoid the common barriers that prevent utilization of services. The guide provides links to information from National and international Developmental Disabilities Organizations and National and State Dental Associations and Federal Organizations. Information is also referenced from Local Corporations and State Universities. Such topics as improving oral hygiene at home and making office visits to the dental office less stressful can be accessed. The websites also provide descriptions of and research about specific types of developmental disabilities. Printable resource guides for patients and families can also be found in many of the websites listed. Information regarding community dental clinics, local events, and donated dental services in Arizona can be accessed in some of the referenced sites.

“You are not healthy without good oral health”
(C. Everett Koop, MD, former US Surgeon General)

Oral health care is the most prevalent unmet healthcare care need among children with and without special needs.

(Newacheck et al. 2000; Yu et al. 2002).

The lists in this guide do not imply any recommendation from ADDPC or ATSU. The information should simply be a resource and should not take the place of regular consultations with a doctor or dentist.

REFERENCE WEBSITES

[American Academy of General Dentistry \(AADMD\)](#)

The AADMD mission is to improve the quality of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities. Available on their website are tools to identify side effects related to specific medications. Look at these guides for more information about what causes xerostomia (dry mouth), acid reflux, and other common side effects.

- [Medication Side Effects Watch List](#)
- [Medication Dental Side Effect Watch List](#)

[American Society of Dentist Anesthesiologists \(ASDA\)](#)

Visit this site if you have questions about dental anesthesia and how it may be beneficial for you in the dental care setting. Learn about dentists who are trained to provide different levels of general anesthesia/sedation.

- [Learn more](#) about the types of patients who are candidates for dental anesthesia
- [Explore](#) the various sedation types
- [Find out](#) what to expect as a dental anesthesia patient

[Autism Speaks](#)

Through a partnership with Colgate, a dental guide and video was developed to provide tips for improving oral hygiene at home. There is also information about how parents and dental professionals can make a visit to the dentist office less stressful and more productive.

- [Dental Toolkit](#) – This tool kit is designed for dental professionals. It provides general information about Autism Spectrum Disorders (ASD) and specific information that may help dental professionals better serve the needs of children with ASD.
- [Arizona Autism Speaks Resource Guide](#) – Locate a Dental Provider

[California Dental Association \(CDA\)](#)

In response to many requests, a dental health and science guide was developed to educate children about the importance of good oral health and preventive dental care. The guide is divided into two parts. One portion focuses on the dental health education for preschool through 2nd grade. The second portion focuses on dental disease and prevention strategies for children in 3rd grade through 5th grade. Each section contains goals and objectives along with age appropriate games and puzzles.

[Centers for Disease Control and Prevention \(CDC\)](#)

This information packed website provides descriptions of specific types developmental disabilities, research about these disabilities, additional printable resource guides for patients, families, and

caregivers and a library of multimedia tools. Learn more about the milestones that children should reach as they are growing, how to live with a disability, and links to other resources.

- [Information on Specific Conditions](#)
 - Attention-Deficit/Hyperactivity Disorder
 - Autism Spectrum Disorders
 - Cerebral Palsy
 - Fetal Alcohol Spectrum Disorders
 - Fragile X Syndrome
 - Hearing Loss
 - Intellectual Disability
 - Kernicterus
 - Muscular Dystrophy
 - Tourette Syndrome
 - Vision Impairment
- [Milestones ages 0 -5 years](#)
- [Additional Free Printable Resource Guides](#)

[Delta Dental of Arizona](#)

A dental insurance company that has a commitment to funding initiatives that improve oral health in the communities they serve. This site provides you with information regarding Arizona community dental clinics, local events, donated dental services, oral health links, and contacts.

[Dental Lifeline Network \(formerly the National Foundation of Dentistry for the Handicapped\)](#)

This national humanitarian organization provides access to compressive dental services for people with disabilities who are elderly or medically at risk. Dental services are provided through a national network of direct service programs that involve several volunteer dentists and other oral health care professionals. “We provide real help for real people with real problems”. Contact this organization to locate events in your area.

[Indiana University - Bloomington](#)

Taking your son/daughter on the autism spectrum to the dentist poses many challenges. This article hopes to make you aware of some of these challenges prior to your first visit, as well as provide some useful ways to deal with them. Included in this article are three main areas that are most often in need of attention: preparation for the dental visit, sensory issues, and communication challenges.

[National Down Syndrome Society \(NDSS\)](#)

This site will walk you through the oral health of people with Down Syndrome. There are several differences in the oral health care for patients with Down Syndrome and it is important that special attention is paid to this situation. Information will be provided on the following main topics:

- Delayed Tooth Eruption
- Sizes and Number of Teeth and the Tongue
- Problems with the Bite
- Gum Disease
- Cavities

[National Institute of Dental and Craniofacial Research \(NIDCR\)](#)

The NIDCR leads the nation in supporting research to improve oral health. As a research institution, the NIDCR does not provide dental care or financial assistance for care. One option for low-cost dental care is visiting dental schools where there are often clinics dedicated to treating patients with special needs. Faculty and students at these clinics have the knowledge and skills to ensure a positive dental experience. Dental schools in your area:

- [A.T. Still University](#) - Arizona School of Dentistry and Oral Health (ASDOH)

Note that ASDOH has a Special Needs Clinic, devoted to treating patients with special needs and an Advanced Oral Care Center to treat patients with complex medical and dental issues.

- [Midwestern University](#)

For other information, regarding referrals to private practitioners please visit:

- [Arizona Dental Association](#)

[National Institute of Dental and Craniofacial Research \(NIDCR\)](#)

This guide provides information regarding developmental and intellectual disabilities and invites patients, families, and caregivers to become more familiar with the strategies utilized in a dental office to provide care. This guide focuses on the overall and specific oral health challenges and strategies for care. The strategies that you learn about that are utilized in the dental office can also be adopted for use each day at home to increase oral health hygiene.

If you scroll to the bottom of this webpage you will find specific booklet series that provide more in-depth information regarding the following topics:

- Practical Oral Care for People With Autism
- Practical Oral Care for People With Cerebral Palsy
- Practical Oral Care for People With Down Syndrome
- Practical Oral Care for People With Intellectual Disability
- Wheelchair Transfer: A Health Care Provider's Guide
- Dental Care Every Day: A Caregiver's Guide

[National Museum of Dentistry](#)

Dedicated to providing the public with access to information about oral health, the National Museum of Dentistry developed the dental resource called “Healthy Smiles for Autism”. This guide provides oral hygiene tips for children with autism spectrum disorder. With an array of colorful images and straightforward instructions, children can develop skills to take care of his or her mouth at home and learn how to independently adopt each step of oral health hygiene.

Look [here](#) for more information from the National Museum of Dentistry:

- MouthPower - Tips for Keeping a Healthy Adult Smile – This oral health resource for older adults features informative oral health tips for adults age 50 and older, including an exploration of how the adult mouth is changing and what to do about it, a special look at unique nutritional issues as we age and an exploration of the connection between the mouth and the body.
- MouthPower – This program provides education about how to brush your teeth, what tobacco can do to your mouth and how to make healthy food choices. Available in English and Spanish.
- Your Spitting Image – This program offers an online exploration of forensics, saliva and bioengineering. Downloadable teacher guides and interactive activities can be used in the classroom.

[Phoenix Children’s Hospital](#)

A prestigious local hospital that provides up to date information on Pediatric Dental emergencies and Children’s dental health including:

- [Anatomy and Development of the Mouth and Teeth](#)
- [Prevention of Oral Problems](#)
- [Common Dental Problems and Concerns](#)
- [Dental Procedures, Dental Health Overview](#)
- Dental Procedures for Children including, Orthodontics / Braces, Fillings, Sealants, and Wisdom Teeth Extraction

[South Carolina Department of Health and Environment Control’s](#)

Here you can find the Oral Health for Families with Special Health Care Needs resource guide. This guide is designed to give parents and caregiver tips on keeping their child’s or teen’s mouth healthy. The information is easy to understand and can help parents and caregivers take an active role in establishing and maintaining good oral health for their child or client. Main topics of this guide include:

- General Home Care
- Nutrition and Oral Health
- Keeping Your Child’s Smile Safe
- Special Conditions and Oral Health

Special Care Dentistry Association (SCDA)

SCDA is a unique international organization of oral health professionals and other individuals who are dedicated to promoting oral health and wellbeing for people with special needs. SCDA has developed an online repository of fact sheets and other resources for patients, families, and caregivers.

Resource topics include:

- Care for Dentures
- Oral Care After Head and Neck Radiotherapy
- Oral care During Head and Neck Radiotherapy
- Oral Care for Children with Autism 1 (English)
- Oral Care for Children with Autism 2 (English)
- Oral Care for Children with Autism (Spanish)
- Oral Care for Children with Down Syndrome (English)
- Oral Care for Children with Down Syndrome (English)
- Oral Care for Children with Down Syndrome (Spanish)

Also, this website provides information on finding a dentist in your area to provide dental services to patients with special needs. Click [here](#) to find a Special Care Dentist in your area.

The Association of State & Territorial Dental Directors (ASTDD)

This website provides information about patients with special needs and their demand for dental care. There is also information regarding the challenges of accessing dental services for patients with special needs and the limitations of the current dental care system. This information can help patients, families or caregivers seek out the best location for dental care. Strategies and other information is also provided regarding the goal to improve the oral health of individuals with special needs through an effective and efficient dental care system.

The Southwest Autism Research and Resource Center (SARRC)

Dental Information in this guide is geared toward the dental professional and includes the following topics:

- Oral Health and Autism Spectrum Disorders
- Relevant dental issues
- Preparation for treatment
- Welcome packet
- Dental tips
- Expectations
- Fact sheets
- Resource guide

Tufts University - Tufts Open Courseware

Tufts University School of Dental Medicine was established in 1868 and plays an integral part in the development of oral health care services and dental education. Faculty involved with providing treatment to patients with special needs has developed learning sessions to educate individuals about a variety of intellectual disabilities and the benefits of Special Care Dentistry. The learning sessions available include:

- Intellectual Disabilities
- Medical Considerations and Syndromes – Cerebral Palsy
- Medical Considerations and Syndromes – Down Syndrome
- Medical Considerations and Syndromes – Autism Spectrum Disorders
- Medical Considerations and Syndromes –Epilepsy (Seizure Disorder)
- Medical Considerations and Syndromes – Polypharmacy
- Medical Considerations and Syndromes – Spina Bifida
- Medical Considerations and Syndromes – Congenital Heart Defects
- Medical Considerations and Syndromes – Sturge-Weber Syndrome
- Medical Considerations and Syndromes – Rett Syndrome
- Medical Considerations and Syndromes – Fragile X Syndrome
- Medical Considerations and Syndromes – Sensory Impairment
- Behavior Management
- Preventive Care in Special Care Dentistry
- Special Considerations in Special Care Dentistry

University of Washington School of Dentistry

This site provides specific fact sheets for mild to moderate manifestations of a number of special need conditions. General fact sheets regarding medical and dental care are also provided. There are multiple fact sheets for Dental Professionals, Medical Professionals, Parents, and Caregivers. Specific fact sheet topics include, but are not limited to:

- Anxiety
- Down Syndrome
- Epilepsy
- Eating Disorder
- Intellectual Disability
- Hearing Impaired
- Cleft Lip & Palate

General fact sheet topics include, but are not limited to:

- Dental guidance
- Medical guidance
- General guidance Parents and Caregivers (English, Spanish, Russian)

For more oral health information please visit these websites:

- [American Dental Association](#)
- [Exceptional Parent Magazine](#)
- [Special Olympics Healthy Athletes](#)

FUNDING DENTAL CARE FOR PATIENTS WITH SPECIAL NEEDS

The National Institute of Dental and Craniofacial Research (NIDCR) provide information on some resources that can help patients, families, and caregivers find and pay for dental care.

Clinical Trials

The NIDCR sometimes seeks volunteers with specific dental, oral, and craniofacial conditions to participate in the research studies they conduct, also known as clinical trials. Researchers may provide study participants with limited free or low-cost dental treatment for the particular condition they are studying.

- Click [here](#) to find out if there are any NIDCR clinical trials that you fit into
- Click [here](#) for a complete list of federally funded clinical trials

Dental Schools

These schools can be a good source of quality, reduced-cost dental treatment. Most of these teaching facilities have clinics that allow dental students to gain experience treating patients while providing care at a reduced cost. Experienced, licensed dentists closely supervise the students. Post-graduate and faculty clinics are available at most schools. Look for these schools in your area:

- [A.T. Still University](#) - Arizona School of Dentistry and Oral Health (ASDOH) – This university has a Special Needs Dental Clinic and a Center for Advanced Oral Health. They have both Graduate and Post-graduate dental students that treat patients with special needs.
- [Midwestern University](#)

Visit the [America Dental Association](#) website for a complete list of dental schools.

Bureau of Primary Health Care

The Bureau of Primary Health Care, a service of the Health Resources and Services Administration (HRSA), supports federally-funded community health centers across the country that provide free or reduced-cost health services, including dental care. To obtain a list of centers contact the HRSA Center toll free at 1-888-Ask-HRSA (1-888-275-4772) or visit their website:

- [Centers in Arizona](#)

Centers for Medicare & Medicaid Services

The Centers for Medicare & Medicaid Services runs three important federally funded programs: Medicare, Medicaid, and Children's Health Insurance Program (CHIP)

- Medicare, 1-800-MEDICARE (1-800-663-4227) – Medicare is a health insurance program for people who are 65 years and older or for people with specific disabilities. Medicare does not cover most routine care or dentures. Currently, Medicare will pay for dental services that are an integral part either of a covered procedure (e.g. reconstruction of the jaw following accidental surgery), or for extractions done in preparation for radiation treatment for neoplastic diseases involving the jaw. Medicare will also make payment for oral examinations, but not treatment, preceding kidney transplantation or heart valve replacement, under certain circumstances. For more information visit the [Medicare website](#) or call Medicare Services.
- Medicaid, 1-877-267-2323 – Medicaid is a state-run program that provides medical benefits – and some dental benefits – to eligible individuals and families. Most states provide limited emergency dental services for adults, while some offer comprehensive services. For more information visit the [Medicaid website](#) or call Medicaid Services.
- Children’s Health Insurance Program (CHIP), 1-877-KIDS-NOW (1-877-543-7669) – CHIP, also a state-run program, is for children in families who earn too much to qualify for Medicaid but can’t afford private insurance. CHIP provides dental services to children up to age 19. Dental services covered this program vary from state to state. Visit the [CHIP](#) or [Arizona CHIP](#) website or call CHIP Services to find children’s dental care programs in your state.

For more information, please visit these websites:

- [American Dental Association](#)
- [AHCCCS – Arizona’s Medicaid Agency](#)
- [Mercy Care](#) & [Mercy Care Advantage](#)

If you are having difficulty finding a provider, please contact the Special Needs Department at the Arizona School of Dentistry and Oral Health, 480-248-8169, and ask Amanda Barstow for assistance.