The Mentally Challenged Patient:

The Experience of a Lifetime

"Bridging the Gap: Tips for Treating a Patient with Autism"

California Dental Hygienists' Association

8th Annual CE Extravaganza

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Putting it in perspective

Autism spectrum disorders (ASDs) are a group of developmental disabilities that are caused by unusual brain development. People with ASDs tend to have problems with social and communication skills. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. ASDs begin during childhood and last throughout a person's life.

www.cdc.gov

www.autismspeaks.org

Staggering Stats

- As many as 1 in 150 children today have some form of an ASD
  - As compared with:
    - Cerebral palsy (1 in 357)
    - Juvenile diabetes (1 in 450)
    - Down's syndrome (1 in 800)
    - Hearing loss (1 in 909)
    - Vision impairment (1 in 1,111)

www.cdc.gov

Staggering Stats

- 3 children per hour are being diagnosed with ASD
- The rate of ASD diagnoses is rising 10-17% annually
- Diagnosis has increased tenfold in the last decade
- 24,000 children are diagnosed with ASD every year

www.cdc.gov

Staggering Stats

- 35 million individuals have autism in the US today
- Prevalence in NJ is significantly higher than the national avg. with 1 in 68 boys affected

www.autismspeaks.org

www.hsph.harvard.edu

Staggering Stats

- The CDC and Prevention have called autism a national public health crisis whose cause and cure remain unknown
- Annual cost in US to care for individuals with autism $35 Billion

www.autismspeaks.org

www.hsph.harvard.edu

Agenda

- **Putting it in perspective**
- **The Basics – Why are we here**
- **Comfort Zones**
- **Start at the beginning**
- **Treatment accommodations**
- **Home Care Therapy**
- **How will I measure my success**
- **When is it time to refer**
- **Long-term impact**

Putting it in perspective

Autism is a developmental delay that includes symptoms such as speech difficulties, lack of eye contact, isolation and no fear of danger.

www.healing-arts.org/children/autism-overview.htm

What is Autism?

Autism is a complex brain disorder that inhibits a person's ability to communicate and develop social relationships and is often accompanied by extreme behavioral challenges.

Impairment in Social Reciprocity

- Reduced interest in and attention to social stimuli
  - May be more interested in equipment and instruments than in dental staff
  - May not readily respond to name, verbal directions, questions, or compliments
  - May not face and observe speaking partners

Impairment in Communication

- Social usage and implied meaning of language
  - May be overly direct, blunt, curt, personal in questions/comments
  - May not respond to cordial greetings from others
  - May interpret idioms, metaphors, and sarcasm very literally and concretely
  - May react unexpectedly and inappropriately to social humor intended to put them at ease

Impairment in Communication

- Reduced social chat and reciprocal conversation
  - May not make small talk or chat socially
  - May not initiate or maintain conversation
  - May not respond to pleasant comments or questions posed by staff
  - May have significant difficulty with open-ended questions, especially those on social topics

The Genetics of Autism

50% chance that another child in the same family will have a related neurobiological disorder.

The Autism "Spectrum"

- Broad range of developmental functioning
  - Cognitive/Intellectual Ability
    - Profound impairments to superior IQ
  - Speech and Language Functioning
    - Functionally mute to very sophisticated language
  - Adaptive Functioning
    - Totally dependent to relatively self sufficient
  - Temperament
    - Intense and highly reactive to calm and passive

What does this mean for our patient population?

- Since the 1970's, nearly two-thirds of people living in institutional settings have been moved into community-based settings, and dental care services that were provided in the institutions are no longer available to them.

Autism is something I have, it is not WHO I am.

Unable to always tell you how I feel.

Tell me exactly what you mean.

I want friends, I just don't know how.

Senses are easily overloaded.

My meltdowns are hard for everyone, especially me.

Love,
Any child with autism

Love me and help me understand your world.

I have different abilities, not a disability.

Focus on what I can do, not on what I can't do.

Explore my world and I will make you smile.

Love,
Any child with autism

AUTISM SPECTRUM DISORDERS

Autism – Pervasive Developmental Disorder (PDD)

Asperger's Disorder

Rett's Disorder

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

Child Disintegrative Disorder

www.iancommunity.org

AUTISM SPECTRUM DISORDERS

Diagnostic Tools

- **Autism Diagnostic Interview – Revised (ADI-R)**
- **Autism Diagnostic Observation Scale (ADOS)**

AUTISM SPECTRUM DISORDERS

Early signs and symptoms

- **No big smiles or other warm, joyful expressions by six months or thereafter**
- **No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter**
- **No babbling by 12 months**
- **No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months**
- **No words by 16 months**
- **No two-word meaningful phrases (without imitating or repeating) by 24 months**
- **Any loss of speech or babbling or social skills at any age**

www.autismspeaks.org

Putting it in perspective
What causes Autism? – Yikes!!

Speculations are as follows:

- **Psychiatric Disorder**
- **Cholosystokinin**
- **Oxytocin and Vasopressin**
- **Amino Acids**
- **Stress and Immunity**
- **Vaccinations**
- **Prenatal Aspartame Exposure**
- **Vitamin A Deficiency**
- **Orphanin Protein**
- **Smoke and Air Pollution**

Theories are as follows:

- **Opioid excess theories**
- **Gluten/Casein theories and relation to Celiac Disease**
- **Gamma Interferon Theory**
- **Free Sulphate Theory**
- **Methylation Theory**
- **Autoimmune Theory**
- **Viral Infection Theory**
- **Action of Secretin Theories**
- **Intestinal Permeability Theories**

Bottom line: There is no answer yet…………

http://www.healing-arts.org/children/autism-overview.htm

Putting it in perspective
What cures Autism? – Yikes!!

Treatment options are as follows:

- **Educational / Behavioral interventions**
  - **ABA (Applied Behavioral Analysis) – Discrete Trials**
  - **Speech / Language Therapy**
  - **Occupational Therapy**
  - **Physical Therapy**
  - **Hippotherapy**
  - **Music therapy**
  - **Social skills training**
- **Medications**
  - **Antidepressants – treats symptoms of anxiety, depression, or obsessive-compulsive disorder**
  - **Anti-psychotics - used to treat severe behavioral problems**
  - **Anticonvulsants – for treatment of seizure disorders**
  - **Stimulants - used to help decrease impulsivity and hyperactivity**
- **Other therapies: There are a number of controversial therapies or interventions. Few, if any, are supported by scientific studies.**
  - **Diet**
  - **Hyperbaric Chambers**
  - **Chelation**

Bottom line: There is no cure yet…………

www.ninds.nih.gov/disorders/autism

Putting it in perspective

"The impact of having a developmental disability is immense for the families affected …. It is important that we treat ASDs as conditions of urgent public health concern, …. and begin intervention as early as possible to enable all children to reach their full potential."

www.cdc.gov

University of Iowa senior students' comfort levels, pior experience, and willingness to treat various underserved populations – pre-extramural survey (N=690)

Population Group	Mean Comfort (s.d.)	Median Comfort	% Comfort: Yes	% with Some Experience	% Willing to Treat in Future
Low income	4.7 (0.5)	5	97.7	68.6	56.1
Frail elderly	3.9 (0.9)	4	64.1	40.5	47.0
Homebound	3.8 (0.9)	4	63.1	11.2	6.2
Medically complex	3.8 (0.8)	4	57.4	46.6	58.2
Mentally compromised	3.7 (0.8)	4	54.5	34.8	33.4
Homeless	4.3 (0.7)	4	84.8	12.3	6.1
Drug user	3.8 (0.9)	4	59.6	36.6	17.9
Other ethnic group	4.8 (0.5)	5	98.4	56.2	55.4
Title XIX	4.6 (0.6)	5	95.0	76.1	34.6
HIV + - AIDS	3.6 (1.0)	3	47.4	22.7	17.1
Jailed	4.0 (0.9)	4	68.7	21.8	2.5
Non-English speaking	3.9 (0.9)	4	64.1	51.1	23.2

Journal of Dental Education, Dec. 2005, Vol69, No12

Bivariate analyses between comfort in treating each underserved population, by gender, years since graduation, and prior experience (N=690)

Population Group	Gender	Years Since Graduation	Experience with Population
Low income	0.2991	0.7086	0.2782
Frail elderly	0.0446	0.8848	<0.0001
Homebound	0.1806	0.0014	0.0008
Medically complex	0.0005	0.5750	0.0054
Mentally compromised	0.0539	0.2945	<0.0001
Homeless	0.1468	0.5403	0.0793
Drug user	<0.0001	0.0026	<0.0001
Other ethnic group	0.6379	0.0818	0.5690
Title XIX	0.7049	0.3878	0.0411
HIV + - AIDS	0.1103	<0.0001	<0.0001
Jailed	<0.0001	0.4028	<0.0001
Non-English speaking	0.0054	0.8578	<0.0001

Journal of Dental Education, Dec. 2005, Vol69, No12

The Basics

Special Olympics study found that "more than half of medical school deans and dental school deans, respectively, said that their graduates were 'not competent' to treat patients with intellectual disabilities," according to Reuters Health, the organization that conducted the study.

The Basics

Surgeon General Satcher, 2002 reports:

- **Health disparities for people with Intellectual Disabilities**
  - **Lack of training of health care providers**
  - **Lack of access to health care providers**
  - **Inadequate Medicaid reimbursements**

The Basics

Minimal Clinical Training in Medicine on Intellectual Disabilities (ID)

- **81% of medical students will graduate without ever having ANY clinical training in how to care for a person with an ID**
- **90% of primary care residency programs offer no formal training in ID**
- **51% of graduating dentists have not treated a patient with an ID**
- **75% admit feeling inadequately trained in this field**

CAN: Curriculum Assessment of Needs Project

The Basics – Access to Care

Recent California state survey of people with ID living in the community documented:

- **Only 11% say that it is easy to find a physician**
- **Only 2.7% say that it is easy to find a dentist**

CAN: Curriculum Assessment of Needs Project

The Basics – Access to Care

What about Pediatric Dentists:

- **Patients with autism are not children forever…*<u>Should we let them age out of dental care?????</u>***
- **Transition to adulthood is critical falling off point for healthcare as providers are no longer available**
- **When new provider is found, families feel they have to start all over again**
- **General providers don't have the resources, tools, training, and funding to meet the needs of these adult patients. Result is illness often unrecognized, misdiagnosed, or undertreated.**

larissa, "A Blind Spot in the System: Health Care for People with Developmental Disabilities

The Basics – Access to Care

Recommended competencies for Health Care Providers:

- **Medical knowledge of developmental disabilities**
- **Compassion and sensitivity**
  - **Good listening skills**
  - **Flexibility**
  - **Understand context in which individuals live and how it may influence treatment**
  - **Be aware of challenges patient faces on a daily basis and types of accommodations they might need**
- **Strong communication and observation skills**
- **Understanding of the health care system**

Kripke, Clarissa, "A Blind Spot in the System: Health Care for People with Developmental Disabilities

THE GOOD NEWS!

<u>Accreditation Standards for Special Needs Patients</u> The language recently reinserted by the Commission on Dental Accreditation is as follows:

In an effort to overcome the virtual absence of educational opportunities to prepare students for the care of patients with special needs, Special Olympics initiated the effort which brought about a modification in the Standards of Accreditation of all dental and dental hygiene schools in the United States. Beginning in 2006, all schools considered for accreditation by the Commission on Dental Accreditation must assure didactic and clinical opportunities to better prepare dental professionals for the care of persons with intellectual and other developmental disabilities.

Access January 2006.

Comfort Zones

Comfort Zones

<u>For the patient</u>

- **These details can be learned through documentation and interviews**
- **They are most often learned through experience with each individual patient**

Comfort Zones

<u>For the practitioner</u>

You will need:

- **an open mind and open heart**
- **more emotional skills than intellectual or clinical skills**
- **to get close to your patient both physically and emotionally**
- **to leave behind your reasoning skills; most times they will not work**

Comfort Zones

"Making a difference in the oral health of a person with autism may go slowly at first, but determination can bring positive results and invaluable rewards"

~ National Institute of Dental and Craniofacial Research

How can you help even if you don't have the "gene"?

- AGD advises: *While we encourage all dental professionals to treat these individuals, the law does not require professionals to accept patients with special needs into their practice. However, they should try to provide some guidance by knowing who does have the experience and education to treat patients with special needs in their community.*

"Special Care: Treating Patients with Special Needs Requires Both Training and Compassion" ***AGD Impact*****, October 2007**

How can you help even if you don't have the "gene"?

- AGD advises: *Being compassionate isn't the law, but dentists experienced with patients who have special needs say that compassion is most of what it takes to treat them, or at least to help them get treatment.*

"Special Care: Treating Patients with Special Needs Requires Both Training and Compassion" ***AGD Impact*****, October 2007**

Start at the Beginning

Start at the beginning

- **The VERY beginning in some cases means: Seek out these patients**
  - **Brochures available in the waiting area on treating a patient with special needs (American Academy of Pediatric Dentistry)**
- **Provide parents that inquire with a form that asks questions about their child – this shows that you understand and care**

Start at the beginning

What the Patient Information form should look like:

- Describe the nature of your child's disability
- Medical
- Dental experience
- Physical functioning
- Sensation
- Communication
- Vision
- Hearing
- Behavior / Emotions
- Oral habits (include eating, chewing, PICA)

Start at the beginning

- During the phone call:
  - Review patient information form in detail
  - Ask what is the best time of day for the appt.
  - Ask the parent to bring the child's favorite music, video, toy, comfort blanket, or other COPING DEVICES
  - Ask the parent to bring a friend who can sit with the child while the forms are reviewed
  - Offer to send photos of office and a dental story home with patient for parent to review

Start at the beginning

"DESENSITIZATION / TRUST BUILDING" APPOINTMENT

- First scheduled appointment should be interview, orientation, and brief exam only (20 mins.)
- **Primary goal is to establish trust**
- **Help parent and patient know that you care about them**
- **Ask parent to choose a location (waiting area, operatory, office, staff lunch room?)**

Top 10: What caregivers need from dental office staff:

1. **Dental office staff have an understanding of the disability and the anxiety that individuals may have about dental visits**
2. **Treat individuals and caregivers with the same respect and dignity as others receive and recognize unique family strengths**
3. **Have short wait times and a low stress, quiet environment, with special or separate waiting rooms**
4. **Speak directly to the individual**
5. **Allow extra time for the appointment**
6. **Listen to caregivers' and individuals' expressed needs (verbal and non-verbal)**
7. **Share complete and unbiased information with families**
8. **Allow caregivers to be present during visit and ask them questions when needed**
9. **See the individual as a person with unique needs, not as a "disabled person"**
10. **Make appropriate referrals and timely follow through with paperwork**

Survey conducted with 230 individuals and caretakers across NY State. By Deborah A Chapin & Robin Worobey with the NY State Developmental Disabilities Planning Council, August 1, 2008

Top 10: What caregivers said they should do for themselves:

1. **Prepare the individual for dental visit through role-play, books, and pictures**
2. **Bring distractions for waiting and exam rooms (books, music, video, games, etc) and offer rewards (prizes, outings, etc)**
3. **Ask for a "get acquainted" visit**
4. **Schedule appointment at a time that is best for the individual (first or last appointment of the day)**
5. **Keep a dental journal of co-payments, medications, treatments, prior visits, referrals**
6. **Make sure the parking lot, building, and office are accessible**
7. **Talk to the dentist and staff before the visit, preparing staff ahead of time and reminding them of the individual's needs, mail or fax a summary letter (ie. patient information form)**
8. **Bring a support person to listen to the dentist/hygienist/assistant, write things down, and help with other children**
9. **Research dental issues in books, journals, and online, and ask lots of questions**
10. **Ask for the same staff each time**

Survey conducted with 230 individuals and caretakers across NY State. By Deborah A Chapin & Robin Worobey with the NY State Developmental Disabilities Planning Council, August 1, 2008

Interview

Medical Information

- **Medications**
- **Seizure Activity**
- **Allergies and/or Sensitivities**
- **Bladder / Bowel Adaptations**

Interview

Dental Experience

- **Previous experiences**
- **Daily experiences**
- **Tolerance level**
- **Home care likes and dislikes**
- **What are the dental health expectations?**

Interview

Oral Habits

- **Overall diet**

Overall diet

Food sensitivities / aversions

- **Glutein / Casein free diet**
- **Food textures - aversions**
- **Sensory stimulation foods**

Interview

Oral Habits

- **Overall diet**
- **Snacking frequency (ABA rewards)**

Interview

Oral Habits

- **Overall diet**
- **Snacking frequency (ABA rewards)**
- **Sensory chewing**

Interview

Oral Habits

- **Overall diet**
- **Snacking frequency (ABA rewards)**
- **Sensory chewing**
- **Clenching / Grinding**
- **Non-edibles / Licking objects**

Interview

Oral Habits – Pica

- **Comes from the Latin word for magpie, a bird known for its large and indiscriminate appetite**
- **Most common in people with developmental disabilities, including autism and mental retardation**
- **Commonly ingested foods include: dirt, clay, paint chips, plaster, chalk, cornstarch, laundry starch, baking soda, coffee grounds, cigarette ashes, burnt match heads, cigarette butts, feces, ice, glue, hair, buttons, paper, sand, toothpaste!, soap**

www.kidshealth.org/parent/emotions/behavior/pica.html

Interview

Physical Functioning

- **Stamina**
- **Breathing difficulties**
- **Range of motion**
- **Upper body strength**
- **Self care strengths and weaknesses**

Interview

Sensory modulation processing disorder

- Sensory processing may be similar to infant -

- **Olfactory – office, perfume, cologne**
- **Auditory – sudden noises, music, high speed handpiece**
- **Gustatory – tastes & textures**
- **Visual – lights, peripheral dominance**
- **Vestibular – chair height & tilt, being "still"**
- **Proximity – people, water**
- **Proprioception – jaw opening, gagging, body position, lead apron**
- **Tactile (Touch/Temp/Texture) – room, gloves, air, cotton, metal**
- **Taste – gloves, chemicals**

Interview

Sensory Issues: ***Sensory modulation processing disorder***

Manifests as one of the following:

- **Over Responsivity – slight input causes extreme reaction**
- **Under Responsivity – requires stronger input to register sensation**
- **Sensory seeking – hypo and hyper sensitivities co-mingle within the same sense**

Interview

Sensation

(Sight, sound, smell, taste, touch)

- **Positive stimulations**

Interview

Sensation

(Sight, sound, smell, taste, touch)

- **Positive stimulations**
- **Negative stimulations**

Interview

Sensation

(Sight, sound, smell, taste, touch)

- **Positive stimulations**
- **Negative stimulations**
- **Pain perception level**
- **Temperature perception level**

Interview

Behavior / Emotions

- **Actions speak louder than words!!**

Interview

Questions to ask regarding possible dental pain….

- **Any changes in behavior or prolonged episodes of behavioral abnormalities?**

Case – John bangs the side of his mouth

- Behavior may be the only form of communication
  - **Behavior changes – begins banging side of his mouth**
  - **Referred to Primary Care Physician**
  - **Referred to Psychiatrist**
  - **Referred back to Psychiatrist**
  - **Referred to ER**
  - **Admitted to ICU**
  - **Patient Dies**

COST = ~ $32,000

Treatment Accommodations

Behavior = Communication

- individuals with autism act out for a reason

- it is not about defiance, it is about coping with some type of anxiety

- they often can not communicate dental pain

- **More aggressive**
- **Reduction in eating habits**

Percentage of children who had specific behaviors "sometimes" or "often".

	Caries free, no toothache (Control) n = 18	Caries free, do not know toothache n = 11	Caries but no toothache n = 14	Both caries and toothache n = 11
Biting things off with their back teeth instad of their front teeth	11	30	50	55
Putting sweets away just after starting eating	6	18	21	82
Starting to cry during meals	6	10	21	27
Having problems with brushing upper teeth	11	28	79	91
Having problems with brushing lower teeth	11	27	79	82
Having problems chewing	6	28	29	73
Chewing on one side	0	18	21	82
Suddenly grabbing his/her cheek	0	36	0	27
Suddenly crying at night	6	18	21	46
Producing more saliva	6	64	7	46
Putting her/his hands in mouth	0	64	21	73

Versloot, J.,Hall-Scullin, E.,Veerkamp, J., Freeman, R.,, "Dental discomfort Questionnaire: its use with children with a learning disability" Spec Care Dentist" 28(4): 140-144, 2008

Interview

Behavior / Emotions

- **Impulsiveness**
- **Frustration level**
  - **Verbal or physical cues**
- **Verbally lose control**
- **Physically lose control**
  - **Pinching self and/or others**
  - **Head banging**
  - **Biting self and/or others**
  - **Self forced vomiting**

Interview

Behavior / Emotions

- **Impulsiveness**
- **Frustration level**
  - **Verbal or physical cues**
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- **Physically lose control**
  - **Pinching self and/or others**
  - **Head banging**
  - **Biting self and/or others**
  - **Self forced vomiting**
- **Techniques for gaining control**
- **Useful words of encouragement**

Interview

Communication

- **Hearing difficulties**
- **Receptive language skills**
  - **Following directions**
  - **Learning new things**
- **Expressive language skills**
  - **Make needs known**
  - **Ability to speak so others understand**
  - **Echolalia**
  - **Verbal and non-verbal cues**
- **Useful words and phrases**
- **Communication device(s)**

Start at the beginning

"DESENSITIZATION / TRUST BUILDING APPOINTMENT"

- **Ask parent to choose a location (waiting area, operatory, office, staff lunch room?)**
- **Orientation – Tell / Show / Do**
- **Brief exam (no instruments) – Let the patient decide where they would like to sit**
- **Reward, Reward, Reward**

Start at the beginning

What did you learn?

The next scheduled appointment should be based entirely on what you learned about the patient at this appointment.

- How much time will you need?
- What do you plan to accomplish?
- What accommodations will be necessary?
- How will you measure success?

*Focus on the patients **abilities**, not their disabilities, to determine what will work.*

Treatment Accommodations

Treatment Accommodations

Providing dental care to the patient with autism is not about doing different procedures, but doing the same thing in different ways.

Treatment Accommodations

Basic Rules
- **Keep the appt. short and sweet**
- **Perform treatment a little bit at a time**
- **A smile and sense of playfulness go a long way**
- **Speak the patient's language**
- **Understand the patient's developmental age**
- **Allow choices for the patient**
- **Establish a relaxed atmosphere**
  - **Keep instruments out of sight**
  - **Keep light out of eyes**
- **Exceptional memories**
  - **Good experience = more cooperation next visit**
  - **Poor experience = difficult future visits**

Treatment Accommodations

Research shows:
- **First dental visit – typical sensory experience**
- **Second dental visit modifications**
  - **no overhead light**
  - **slow moving repetitive color lamp was added**
  - **LED headlamp was used instead of dental light**
  - **soothing music playing**
  - **pt. wrapped in heavy weighted vest**
  - **dental chair vibrates**
- **Results – anxiety levels decreased in ALL children**
  - **Typical children – 3.69 mins to 1.48 mins***
  - **DD children – 23.44 mins to 9.04 mins***

**** duration of anxious behavior***

Science Daily, Feb 22, 2009

Treatment Accommodations

Simple Tools -***"Sometimes the best tool for the job is the Simplest"***
- **Positive reinforcement – Be sincere, consistent praise, high fives**
- **Extinction (ignore)**
- **Consistency (operatory, personnel)**
- **Tell-Show-Do**
- **Distraction (counting, singing)**
- **Calm demeanor, using gentle tone of voice**
- **Easy requests first, build to more difficult requests**
- **Pre-appt preparation/Familiarization & Modeling**

Folse, G., Glassman, P., Miller, C., "Serving the Patient with Special Needs" *Access,* January 2006

Treatment Accommodations

Familiarization Method – *"D-termined Program of Repetitive Tasking and Familiarization in Dentistry"….Dr. David Tesini*
- **One new step at each visit**
- **Parents/caregivers must practice routine at home**
- **Encourage caregivers to "play dentist" at home**

<u>Three Key Factors</u>

1) Eye Contact – "Look at me"

2) Educational Modeling (clear direction) – "Hands on your tummy", "Feet out straight"

3) Counting Framework – "Let me do it for a count of 10"

www.specializedcare.com

Treatment Accommodations

Billing:
- ***3 appts. 15 min each = 1 appt 45 mins***
  - ***No more than 2 weeks between appts.***
  - ***Caregiver should be working on specific skills between visits***
- ***Choose which of the 3 appts. to charge for exam and prophy***
- ***ADA Code for Behavior Management 09920***

www.specializedcare.com

Home Care Therapy

Home Care Therapy

DAILY FULL MOUTH DISINFECTION

- **Begin thinking of toothpastes and mouthwashes as medications and of the toothbrush as the device used to deliver the medication.**
- **Consider the use of terms such as debridement and medication instead of "brushing".**
- **These thoughts can be captured in conversation and in a letter provided for caregivers.**

Elliott-Smith, S., "Special Products for Patients with Special Needs" Access, January 2006

Home Care Therapy

- **Start with baby steps**
  - **Set timer for 5 – 10 seconds for first brushing session**
  - **Always allow patient to brush alone, even if only 1 second at first**
- **Recommend higher frequency of brushing at first, then reduce frequency as quality of session increases.**

Home Care Therapy

- Use analogy – Home care therapy is another goal for the IEP (Individualized Education Plan)
  - Individual must be conditioned to accept this routine (just like all other self care routines)
  - Use pictures (PECS) to show progress through the routine ***www.do2learn.com***
  - Break down the routine
    - Put paste on the brush
    - Wet the brush
    - Brush 1 – 32 teeth
    - Rinse
    - Floss
    - Apply fluoride
  - Ideal therapy 2x/day

Home Care Therapy

- **Crucial that care-giver be provided with hands-on training**
- **Issues of accountability should be discussed (Might simply ask and document, "Who will be accountable for success or failure of this patient's oral health?")**

Another resource for caregivers…..

Overcoming Obstacles to Dental Health: 4th Edition *A Training Program for Caregivers of People with Special Needs* (includes training manual, workbook, and DVD)

University of the Pacific
Arthur A. Dugoni School of Dentistry
Pacific Center for Special Care
2155 Webster Street
San Francisco, CA 94115

415-749-3384

Home Care Therapy

<u>Patients with seizure disorders</u>

- **Emphasize with caregivers that traumas require immediate professional attention**
- **Review care for an avulsed tooth**
  - **A child's tooth might be preserved under the tongue or in the buccal vestibule in the parent's mouth.**
  - **Can be stored in saline, milk, or water until a better preservation solution is available. (Hank's solution, Sav-A-Tooth kit)**

National Center for Emergency Medicine Informatics www.ncemi.org

Fluoride Application Considerations

Caries Risk Reduction Regime

- **Patients with disabilities that necessitate the help of a caregiver to provide daily oral home care will benefit tremendously**
- **If a hospital visit is the only way to accomplish restorative care for a patient with special needs, prevention takes on a whole new level of importance**

Majeski, J CRA/CAMBRA and the Dental Hygiene Process of Care Access, Feb 2009.

Fluoride Varnishes

- **FDA approval — cavity liner and desensitizing agent only**
- **In Europe, used for caries reduction:**
  - 25–45% caries reduction
  - Easy application
  - Sets rapidly on contact with saliva
  - Now available in unit dose
  - Less ingested during treatment
  - No brushing or eating hard foods, 3–4 hours

Topical Fluorides For Self Care Therapy

	Acidulated Phosphate Fluoride (APF)	Neutral Sodium Fluoride (NaF)	Stannous Fluoride (SnF_2)
Gels	.5% / 5,000 ppm PhosFlur®	1.1% / 5,000 ppm NeutraCare® PreviDent®	0.4% / 1,000 ppm Stop® GelKam® OmniGel® GelTin®
Rinses	.044% / 440 ppm PhosFlur®	0.2% / 900 ppm Fluorinse® PreviDent® 0.05% / 225 ppm Fluorigard® Reach® Act® .02% / 90 ppm Listermint®	0.1% / 250 ppm Perio Rinse - .63 Stannous

Topical Fluorides For Self Care Therapy

	Acidulated Phosphate Fluoride (APF)	Neutral Sodium Fluoride (NaF)	Stannous Fluoride (SnF_2)
Dentifrices	Not available	0.22% / 1,000 ppm	0.4% / 1,000 ppm
OTC Dentifrices		0.22% / 1,000 ppm	
Rx Dentifrices		1.1% / 5,000 ppm Prevident 5000 Plus, Prevident 5000 Booster, Fluoridex Daily Defense	

Comparison: Self Care Fluoride Rinses

	0.05% NaF (Act®, Fluorigard®)	0.2% NaF (Fluorinse®, PreviDent®)
Documented Effectiveness	Clinically proven to reduce caries and promote remineralization	Clinically proven to reduce caries and promote remineralization
F Strength	225 ppm	900 ppm
Drug Status	OTC	Rx
pH	7.0	7.0
Frequency	Daily	Weekly
Precautions	Not recommended for children under 6; alcohol-free preferred	Not recommended for children under 6; alcohol-free preferred

Role Of Saliva

- **Produces salivary pellicle**
- **Antimicrobial**
- **Clears bacteria and carbohydrates; buffers acids**
- **Contains calcium / phosphate / fluoride**
- **Lubricates oral mucosa**
- **Mediates taste acuity**

Medications Creating Xerostomia

Amphetamines	**Antimicrobials**
Analgesics, Narcotics	**Antipsychotics**
Anti-inflammatories	**Asthma drugs**
NSAIDS	**ACE inhibitors**
Anticonvulsants	**Calcium Channel Blockers**
Anti-anxiety drugs	**Gastric Acid drugs**
Antidepressants	**Smoking Cessation drugs**
Antihistamines	

How will I measure my success?

How will I measure my success?

- **Measure your success exactly the same way you do with all patients in the practice**
  - **How do the patient and the caregiver feel about coming to see you?**
  - **How are they responding to treatment?**
  - **Document your successes including techniques that worked during treatment.**
  - **Evaluate actual home care routine.**
  - **Any new disease?**

How will I measure my success?

The Frankl Scale:

assessment of behavior

Category 1:	**refusing care**
Category 2:	**reluctant, uncooperative**
Category 3:	**cooperates, but cautiously**
Category 4:	**positive cooperation**

Document status at each visit.

How will I measure my success?

- **For support, advice, tips, tricks - Special Care Dentistry Association**
- **Follow-up phone call at 2 weeks, 5 weeks, and 12 weeks**
  - **Parents will appreciate concern**
  - **Your recommendations stay top of mind**
  - **Great way to market the practice**
- **Re-evaluation appointment (3 – 6 mos)**

When is it time to refer?

When is it time to refer?

- ***Care-givers and parents know the patient so well, use their insights to help make this decision.***
- ***Help educate them about the alternatives.***
  - ***Educational setting***
  - ***Hospital setting***
  - ***Pediatric dental office***
  - ***Other resources in your area***

Long term impact

Long term impact

For the patient ….

- **Life long dental health**
- **Another person they know who cares about them**
- **One less event to get anxious about**

Long term impact

For the patient's family….

- **The feeling of acceptance**
  - **Many families do not even bring their children with autism to church**
- **An incredible trust that they will consistently tell others about**

Long term impact

For you….

- **Reap the rewards of your success**

Glassman: "It's very rewarding when you stretch yourself a little bit beyond where you think you can go, and then you do some good for somebody."

Folse, G., Glassman, P., Miller, C., "Serving the Patient with Special Needs" *Access,* January 2006

Long term impact

For you….

- **Reap the rewards of your success**

Miller: "People don't care how much you know until they know how much you care."

Folse, G., Glassman, P., Miller, C., "Serving the Patient with Special Needs" *Access,* January 2006

Long term impact

For you….

- **Reap the rewards of your success**

Folse: **Describes the rewards of treating patients with special needs in terms of a *DIVINE REWARD.***

"It's hard to describe the elation one can feel when a patient who doesn't speak to anyone speaks to you."

Folse, G., Glassman, P., Miller, C., "Serving the Patient with Special Needs" *Access,* January 2006

"To the world you might just be one person, but to one person you just might be the world."

Anonymous

Long term impact

For the practice….

- **Referrals from family and friends**
- **Reputation of staff: caring, thoughtful, patient, kind**
- **Opportunity to meet and help some wonderful families**

Long term impact

<u>"Word of Mouth" advertising is extremely powerful</u>

~ In order to *compel* the customers to *want* to share their good experience with their friends, you must make the *process* **memorable**, going *beyond* what is expected.

www.profitadvisors.com/word

Long term impact

Enjoy an experience of a lifetime!! ***We come this way once…How often do we get a chance to impact a life in a major way?***

Resources used in this presentation

- *www.autisminfo.com*
- *www.healing-arts.org*
- *www.do2learn.com*
- *www.cdc.gov*
- *www.arktherapeuticservices.com*
- *www.iancommunity.org*
- *www.mun-h-center.com*
- *www.ninds.nih.gov*
- *www.autismspot.com*
- *www.crosstex.com*
- *Journal of Dental Education, Dec. 2005, Vol69, No12*
- *www.sensorycomfort.com*
- *www.woodlaketechnologies.com*
- *Folse, G., Glassman, P., Miller, C., "Serving the Patient with Special Needs" Access, January 2006*
- *Majeski, J CRA/CAMBRA and the Dental Hygiene Process of Care Access, Feb 2009.*
- *Science Daily*, Feb 22, 2009

Resources used in this presentation

- *www.specializedcare.com*
- *Elliott-Smith, S., "Special Products for Patients with Special Needs" Access, January 2006*
- *www.profitadvisors.com/word*
- *www.autismspeaks.org*
- *"Special Care: Treating Patients with Special Needs Requires Both Training and Compassion" AGD Impact, October 2007*
- *Versloot, J.,Hall-Scullin, E.,Veerkamp, J., Freeman, R.,, "Dental discomfort Questionnaire: its use with children with a learning disability" Spec Care Dentist" 28(4): 140-144, 2008*
- *www.eparent.com*
- Kripke, Clarissa, "A Blind Spot in the System: Health Care for People with Developmental Disabilities
- www.snoezeleninfo.com
- www.thewingmensite.com
- "Standards for Clinical Dental Hygiene Practice" www.adha.org
- www.pedisedate.com

Organizations and Other Resources

- The Special Care Dentistry Association (SCDA) ***www.scdonline.org***
- *The National Foundation of Dentistry for the Handicapped (NFDH)* **http://nfdh.org**
- *The National Institute for Dental and Craniofacial Research (NIDCR)* ***www.nidcr.nih.gov***
- The American Academy of Developmental Medicine and Dentistry (AADMD) ***www.aadmd.org***
- National Survey of Children with Special Health Care Needs ***www.cshcndata.org***

Resources for the future

- ***National Oral Health Information Clearinghouse (NOHIC)***

  301-402-7364

  www.nohic.nidcr.nih.gov

  Order: Rolodex Card, Publication Order Form, and Practical Oral Care – Dental Provider's Kit

  Contains: Caregiver's Guide to Dental Care Everyday, Continuing Education, and Booklets specific to a number of disabilities including Autism.

Resources for the future

- ***American Academy of Pediatric Dentistry***

  211 East Chicago Ave, Ste. 700

  Chicago, IL 60611

  Brochure: "Dental Care For Your Special Child"