Progress and Challenges Meeting the Oral Health Care Needs of Adults with Special Needs Conditions

Malieka Johnson, DDS
General & Adult Special Needs Dentist
Community Health & Private Practice
At the conclusion of this discussion, participants should be able to:

1. Recognize the continued need for oral health access in the adult special needs community and identify where they can help meet the need.

2. Describe components of a functional model to successfully treat adults with special needs conditions.

3. Apply basic methods for treating adults with special needs conditions.
Brief Bio

• Psychology B.S. – UCSD, 2003
• D.D.S. – UCLA, 2011
• GPR – Rancho Los Amigos National Rehabilitation Center, 2012

© October 2017 Malieka Johnson, DDS The Boss with The Floss
What is considered a special needs condition?

- Autism
- Angelman syndrome
- Developmental disability
- Down syndrome
- Cerebral Palsy
- Chromosomal Abnormalities
- Coffin-Siris syndrome
- Emotional disorder/ Psychological (ex. Phobias)
- Epilepsy
- Fragile X syndrome
- Geriatrics
- Intellectual disability
- Prader-Willi
- Seizure disorder
- Severe/Complex medically compromised
- Spinal cord injury
- Traumatic brain injury
- William’s syndrome
- And many more....

Spectrum: Mild, Moderate, Severe
How many people are affected with IDD’s?

1.5% - 2.5% Total U.S. population (4.6 – 7.7 million)

San Diego County > 25,000 served by the San Diego Regional Center

The number of adults with disabilities is increasing.


© October 2017 Malieka Johnson, DDS  The Boss with The Floss
Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports

Report Released to Coincide with 22nd Anniversary of the ADA (Americans with Disabilities Act of 1990)
Who serves the special needs community?

- State & federal education departments special education programs
- Medicaid/Medicare
- Disability Organizations
- Regional Centers
- Medical, Dental, Behavioral Health, Social Work
Oral Health Needs Assessment

- Research project conducted Sept 2013 – April 2014
- Team consisted of:
  Malieka Johnson, DDS, Diana Zschaschel, DDS San Ysidro Health Center, Tracy Finlayson Ph.D, San Diego State University (SDSU), Denise Anderson, RDHAP, San Diego Regional Center
- Over 400 adults with IDD’s were screened

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Research Presentations

- **NNOHA** *(National Network for Oral Health Access)*
  Conference (Colorado), Poster - November 2013

- **NNOHA** Conference (Florida), CE Speaker - August 2014

- **AADMD** *(American Academy of Developmental Dentistry and Medicine)*
  Conference (Los Angeles), CE Speaker - July 2015
High Risk Population

- Mental challenges
- Physical limitations
- Behavioral challenges
- Support system limitations
Barriers to Access

Traditional barriers
Location, transportation, insurance, costs, support system, and fears.

Non-traditional barriers
Shortage of number of willing providers, lack of provider experience and comfort, and wavering institutional support.
Autism Spectrum Disorder
Dental Considerations

- Sensory deficits/sensitivities
- Social interaction challenges
- Smells
- Visual Impairments
- Behavior challenges
- Communication difficulties
- Oral hygiene varies

Reference: Thearc.org
Cerebral Palsy

- Uncontrolled movement
- Primitive reflexes
- Mental capabilities
- Seizures
- Visual Impairments
- Hearing loss/Deafness
- Dysarthria
- Gastroesophageal Reflux

Cerebral palsy is...

- non-life-threatening
- not contagious
- incurable
- non-progressive
- manageable
- permanent
- chronic

© October 2017 Malieka Johnson, DDS The Boss with The Floss

Image: dawn.com
Cerebral Palsy
Dental Considerations

- Bruxism
- Periodontal Disease
- Caries
- Medication-induced gingival hypertrophy
- Dysphagia
- Hyperactive bite and gag reflexes
- Trauma and injury

Photo: pinehurstdentist.com

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Most mild-moderate intellectual disability (ID)
- Some severe ID
- Developmental delays (ex. speech and language)
- Behavior management
- Medical conditions
- Cardiac disorders
- Hypotonia
- Compromised immune systems

Down Syndrome

Reference: ndss.org
Down Syndrome

Dental Implications

- Periodontal Disease
- Dental Caries (tend to be less)
- Macroglossia
- Vaulted Palate
- Malocclusion (open bite)
- Tooth anomalies (missing, delayed, malformations)

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Epilepsy/Seizure Disorder
Dental Implications

- Varying levels of oral hygiene
- Bruxism
- Medication-induced gingival hypertrophy
Intellectual Disability

A below average cognitive ability

- Mental Challenges (IQ ≤ 70-75)
- Behavior Challenges (Significant inability to adapt in everyday behaviors)
- Physical Challenges
- Associated with: Autism, Down Syndrome, Fragile X, FAS
- May concur with
  - Cerebral Palsy
  - Cardiovascular anomalies
  - Seizures
  - Visual Impairments
  - Hearing Loss/Deafness
Intellectual Disability
Dental Implications

- Periodontal Disease
- Dental Caries
- Malocclusion
- Missing, delayed, hypoplastic teeth
- Damaging oral habits
- Trauma and Injury

Photo Source: pintrest.com

© October 2017 Malieka Johnson, DDS The Boss with The Floss
What are best care practices?

- **Who should treat these patients?**
  - General dentist, pediatric dentist, special needs dentist,…

- **Where are these patients best cared for?**
  - Community health center, hospital, residency, private sector,…

- **How should treatment be administered?**
  - Stabilization, sedation, GA,…
  - Why can’t we just go to children’s hospital?

- **What support systems are in place to ensure success?**
  - Insurance, financial, access, family, caregiver, transportation,…
Customized and Integrated Team Approach
Regional Centers

- Dept. of Developmental Services (DDS)
- 21 Regional Centers in CA
- Assessment and Diagnosis
- Counseling
- Advocacy
- Legal protection (conservator, legal authorized representative)
- Strategic partner

Mission of San Diego Regional Center (sdrc.org)
To serve and empower persons with developmental disabilities and their families to achieve their goals with community partners.

© October 2017 Malieka Johnson, DDS  The Boss with The Floss
Components of a Functional Model

- Patient
- Dentist, RDA, DA (Team)
- Family/Caregivers
- Regional Center
- Community Network
- Collaboration with other healthcare providers (PCP, Specialists)
- Frequent Recalls (Multiple benefits)
- Transportation/Day Programs

Customized and integrated team approach
<table>
<thead>
<tr>
<th></th>
<th>Basic methods for treatment success</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No Fear</td>
</tr>
<tr>
<td>2.</td>
<td>Patience</td>
</tr>
<tr>
<td>3.</td>
<td>Flexibility</td>
</tr>
<tr>
<td>4.</td>
<td>Mindfulness</td>
</tr>
<tr>
<td>5.</td>
<td>Safety</td>
</tr>
<tr>
<td>6.</td>
<td>Managing expectations</td>
</tr>
<tr>
<td>7.</td>
<td>Behavior Management</td>
</tr>
<tr>
<td>8.</td>
<td>Lift Systems</td>
</tr>
<tr>
<td>9.</td>
<td>Props/Supports</td>
</tr>
<tr>
<td>10.</td>
<td>Stabilization device</td>
</tr>
<tr>
<td>11.</td>
<td>Education</td>
</tr>
<tr>
<td>12.</td>
<td>Medical Clearance</td>
</tr>
<tr>
<td>13.</td>
<td>Desensitization</td>
</tr>
<tr>
<td>14.</td>
<td>Larger Rooms</td>
</tr>
<tr>
<td>15.</td>
<td>Extra help</td>
</tr>
</tbody>
</table>
If the general dentist, dental hygienist or dental assistant has not had exposure or training in working with or treating patients with special needs conditions, they may feel intimidated and shy away from it. This reluctance can create an unintentional barrier to access to care.

NO FEAR !!!
Patience & Purpose are Paramount
Be Flexible

- Physically - Go to patient (within limits)
- Mentally - No, not today

© October 2017 Malieka Johnson, DDS  The Boss with The Floss
Mindfulness

present?
present?
present?
present?

Body Position
Conversation
Attention

mindfulness

noun
1. the quality or state of being conscious or aware of something, their mindfulness of the wider cinematic tradition
2. a mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique.

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Extreme Team & Patient FocUS

- Get a feel for your patient
- Limit extraneous conversations
- Complete attention on patient
- Positive reinforcement throughout procedure
- Interpreting and anticipating behavior
Safety Alert

- Patient
- Assistants
- Dentist
- Caregiver
- Family

Image: Pintrest.com

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Risk of a medical emergency is increased
Extra awareness is required
Water/saliva cannot back up
Extra suction
Mouth prop
Be ready for quick movements
Managing Expectations

- Yes today and No tomorrow
- Sometimes 1st visit is just that, a visit
- Multiple attempts
- Don’t force it
Behavior Management

- Mouth Prop (Molt, Open Wide, Bite Block – Use caution!!)
- Papoose/Stabilization Board
- Sound Therapy (pt. dependent)
- Aromatherapy (pt. dependent)
- Visual stimulation (pt. dependent)
- Positive Reinforcement
- Bribery (Money, Food, Games, Books, Activities)
Move quickly
Head Stabilization
Extra assistants
Team Approach
Medication
Sedation

Behavior Management

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Ongoing Education

- Parents
- Caregivers
- Community
- Providers
- Staff
- Institutions
Medical Clearances

- Don’t always need
- If in doubt request
- Usually requested for same conditions as patients without special needs conditions (i.e. knee replacement or medically complex)
Desensitization Works

- Acclimating patient to clinic
- Acclimating patient to operatory
- Acclimating patient to dental chair
- Showing instruments
- Brushing teeth – TSD
- Exam

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Case Study: D.J., an 18 year old, Caucasian, male with autism, intellectual disability, sensory sensitivity
Accompanied by: Mother and father
CC: “It’s hard to brush his teeth.”
Appointment #1 (2/15/17)

- Pt. wouldn’t sit in dental chair
- Pt. uncooperative (raise hands)
- Pt. sat in the visitor chair
- Pt. allowed for quick visual exam only
- Pt. would not allow radiographs

Observation: Recommended desensitization
Appointment #2 (2/20/17)

- TSD with dental chair
- Pt. sat in dental chair multiple times for a few moments.
- Pt. expressed nervousness when chair moved.
- At end of appointment D.J. smiled and displayed some increased comfort.
- No radiographs taken

Observation: Mild progress
Appointment #3 (3/1/2017)

- Pt. sat in chair, TSD
- Pt. did not allow for radiographs
- Pt. was anxious but allowed us to brush his teeth with regular toothbrush

Observation: Mild-moderate progress
Appointment #4 (3/14/2017) – SUCCESS!
- Pt. cooperated for exam
- Pt. allowed us to take radiographs
- Pt. cooperated for prophy

Observation: Treatment success, recommend frequent recalls to sustain progress.
Appointment #5 (6/15/2017)

- Pt. sat in chair
- Pt. cooperated for placement of fluoride varnish

Observation: Sustained progress
Appointment #6 (7/16/17)
- Pt. sat in chair
- Pt. cooperated for prophy

Observation: Sustained progress
Customized Special Needs Room

- Wheelchair tilt-lift
- Wheelchair lift
- Oversized rooms
- Door for privacy
- Stabilization Board
- Nitrous Oxide
- Wall art, music, videos
- Extra seating
Moving Forward

Future Ideas for Adult Special Needs Dentistry

- Increase training in dental schools (ex. ASDOH)
- More residency programs (ex. Rancho Los Amigos)
- Special Needs Dentistry as a specialty (Includes Seniors, Medically Complex, Adults with IDD’s, Phobic Patients)
Moving Forward

Future Ideas for Adult Special Needs Dentistry

- Sensory Adaptive Dental Environments (SADE)
- Continuing education training
- Increasing awareness of need through advocacy and research

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Recognize the continued need for oral health access in the adult special needs community and identify where they can help meet the need.
At the conclusion of this discussion, participants should be able to describe components of a functional model to successfully treat adults with special needs conditions.
Review Objective 3

At the conclusion of this discussion, participants should be able to apply basic methods for treating adults with special needs conditions.
Final Words of Encouragement

- Huge impact opportunity
- Patience and perseverance
- Success appears in different forms
- You and your team can do it!
References

- U.S. Department of Health and Human Services
- National Institutes of Health
- National Institute of Dental and Craniofacial Research
- San Diego Regional Center (sdrc.org)
- The Arc (Thearc.org)
- U.S. Census (census.gov)
Patient photos and videos have been consented for use by patient or patient’s legal authorized representative. Other photos used for educational purposes have been referenced accordingly.

© October 2017 Malieka Johnson, DDS The Boss with The Floss
Thank you for your attention!

Contact Information

Malieka Johnson, DDS
General & Adult Special Needs Dentist
Email: Thebosswiththefloss@gmail.com
Phone: (619) 518-9000