Uncharted Waters: Caring for the Aging Developmentally Disabled Patient

Roseann Mulligan DDS, MS
Ostrow School of Dentistry
University of Southern California
Objectives

• Identify the many changes in life circumstances, physical attributes, health conditions and social stressors that are seen in aging individuals.

• Recognize how the characteristic physical, mental and emotional findings of developmentally disabled individuals are further impacted by aging.

• Compare the differences in occurrence and outcomes of aging to individuals with developmental disabilities.

• List resources for further information about oral health perspectives and supports for individuals aging with a developmental disability.
What are Developmental Disabilities?

- A diverse group of severe chronic conditions that are due to mental and/or physical impairments.
- Result in problems in major life activities such as language, mobility, learning, self-help, and independent living.
- Begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime.
Scope of Individuals Affected

- Developmental disabilities affect 13% of children < 18 years of age in the United States.
- Substantial financial and social costs for affected families, educational and health care systems.
In Non-Developmentally Disabled Individuals

Typical aging changes in

• life circumstances
• physical attributes
• health conditions
• social stressors
Developmentally Disabled Individuals

Aging changes in
• life circumstances
• physical attributes
• health conditions
• social stressors

Compounded by
• Lifelong adaptations and confrontations
Spectrum of Robust Health and Frailty in Older Adults

- **NOT FRAIL**
  - Robust
  - Resilient

- **VULNERABLE**
  - Decompensates with minor external stress
  - Poor recovery
  - Onset of frailty

- **FRAILTY**
  - Adverse outcomes
  - High risk of disability and death

- **ENDSTAGE**
  - Frailty/pre-death
Clinical Phenotype of Frailty

- Hallmark is age-related **vulnerability** to stress
- Associated with adverse health outcomes
- Results from
  - disease precipitants
  - stressors
  - declines in
    - physiologic function and reserve
### Triggers for Challenging Behavior in Persons with Mental Retardation

<table>
<thead>
<tr>
<th>Type of Stressor</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transitional phase</td>
<td>Change of teacher or residence; adolescence; retirement of patient</td>
</tr>
<tr>
<td>Interpersonal loss or rejection</td>
<td>Loss of parent, job, romantic partner</td>
</tr>
<tr>
<td>Environmental</td>
<td>Stress at group home or day program</td>
</tr>
<tr>
<td>Family, social support problems</td>
<td>Neglect from family, friends, caregivers; abuse</td>
</tr>
<tr>
<td>Medical or psychiatric illness</td>
<td>Tooth pain; depression</td>
</tr>
<tr>
<td>Anger, frustration</td>
<td>Being teased; inability to complete tasks</td>
</tr>
</tbody>
</table>

Importance of Functional Reserve

- Redundancy of structure and function in all organ systems
- 30% of human organ capacity adequate for normal organ function
- Provides 70% safety margin
- Excess capacity important when organism stressed

- With aging a significant decline
<table>
<thead>
<tr>
<th>Nutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>In the Developmentally Disabled</strong></td>
</tr>
<tr>
<td>• Various needs for energy and growth</td>
</tr>
<tr>
<td>• May over or under eat</td>
</tr>
<tr>
<td>• May be under or over weight</td>
</tr>
<tr>
<td>• May be bothered by food textures, temperatures, noises.</td>
</tr>
<tr>
<td>• May be uninformed about food choices</td>
</tr>
<tr>
<td>• May take medications that affect appetite &amp;/or taste</td>
</tr>
</tbody>
</table>

| **In the Elderly** |
| • Altered nutritional requirements |
| • Change in feeding drive |
| • Altered taste |
| • Decrease in need for calories |
| • Increase in need for nutrient dense food |
Example of a Dysfunctional Pathway

- Altered Nutritional Status
- Lack of Exercise
- Reduced Muscle Mass
- Muscle Weakness
- Early Hip and Knee Replacements
- Arthritis
- Hip Dislocations
- Reduced Ambulation
- Scoliosis and Skeletal Deformities
- Decreased Respiratory Capacity

Aging With a Developmental Disability

Person with a Disability

- Effects of the disability and its treatment
- Limited access to quality health care
- Inadequate funding for health care

- Decreased Quality of Life
- Lifestyle effects
- Lack of knowledge about aging for people with DD
- Normal effects of aging
- Negative attitudes about people with disabilities

From Leonard L. Magnani, M.D., Ph.D. Access Attitudes and Aging September 25, 2007
Intellectual Disability in the US

• 3% of US population has a developmental disability
  http://www.naswdc.org/research/naswResearch/0707Developmental/default.asp

• Current estimated U.S. Population: 310,431,288
  http://www.census.gov/population/www/popclockus.html

• Approximate number of US population with a developmental disability: over 9 million

• Rosa’s Law
  – signed by President Obama October 5, 2010
  – replaces the term mental retardation with “intellectual disability” and “individuals with an intellectual disability.”
Aging with a Developmental Disability (DD)

• Faster aging process than the general population.
• Physical changes occur in the 40s and 50s typically seen in able-bodied 70 or 80 year olds.
• Physicians may not always recognize a problem in a 50-year-old patient that would be recognized if the patient were 80 years old.
• Often these patients see the least experienced members of the health care team
  – Resulting in misdiagnosis and further co-morbidity.

Variations in Health Conditions Among Disabled Adults in Primary Care: Results

- Hypothesis: Adults with disabilities more likely to have common health conditions compared to adults without disability in the same practice.
- Retrospective record review of N = 3553 patient records
- Subjects matched by age group stratification
  - n = 1449 patients with disability
  - n = 2084 patients without disability (Comparison Group)
  - 9 yrs follow-up for disability group and 7 yrs for no disability
- Disabilities included
  - sensory impairments (n = 117)
  - developmental disabilities (n = 692)
  - trauma-related impairments (n = 155)
  - psychiatric impairments (n = 485).

**Adjusted\(^a\) Odds Ratio (and 95% Confidence Interval)**

for Health Conditions with Lower Risk Among
Individuals with Developmental Disabilities Compared
to Patients without A Disability

<table>
<thead>
<tr>
<th>Primary Disability</th>
<th>Health Condition</th>
<th>Adjusted Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental disability</td>
<td>Cancer</td>
<td>0.44 (0.27, 0.73)</td>
</tr>
<tr>
<td></td>
<td>Coronary artery disease</td>
<td>0.42 (0.24, 0.74)</td>
</tr>
<tr>
<td></td>
<td>Obesity</td>
<td>0.78 (0.65, 0.94)</td>
</tr>
</tbody>
</table>

\(^a\)Adjusted for age, gender, race, practice location, starting BMI, and tobacco use.

- DD patients with developmental disabilities were less likely to have coronary artery disease, cancer, and obesity.
<table>
<thead>
<tr>
<th>Primary Disability</th>
<th>Health Condition</th>
<th>Adjusted Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory</td>
<td>Congestive heart failure</td>
<td>3.19 (1.73, 5.88)</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>4.40 (2.04, 9.49)</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>2.33 (1.46, 3.71)</td>
</tr>
<tr>
<td></td>
<td>Seizures</td>
<td>11.2 (5.69, 21.9)</td>
</tr>
<tr>
<td></td>
<td>Transient ischemic attacks</td>
<td>3.73 (1.70, 8.16)</td>
</tr>
<tr>
<td></td>
<td>Death</td>
<td>1.92 (1.07, 3.45)</td>
</tr>
<tr>
<td>Trauma</td>
<td>Chronic obstructive pulmonary disease</td>
<td>2.04 (1.26, 3.32)</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>16.5 (8.79, 31.1)</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>2.36 (1.64, 3.40)</td>
</tr>
<tr>
<td></td>
<td>Seizure</td>
<td>21.5 (12.3, 37.4)</td>
</tr>
<tr>
<td>Developmental</td>
<td>Dementia</td>
<td>7.00 (4.19, 11.7)</td>
</tr>
<tr>
<td></td>
<td>Seizure</td>
<td>29.3 (19.1, 44.9)</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Anxiety</td>
<td>1.40 (1.03, 1.91)</td>
</tr>
<tr>
<td></td>
<td>Congestive heart failure</td>
<td>1.94 (1.36, 2.78)</td>
</tr>
<tr>
<td></td>
<td>Chronic obstructive pulmonary disease</td>
<td>1.77 (1.31, 2.39)</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>3.21 (1.94, 5.31)</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>1.49 (1.15, 1.92)</td>
</tr>
<tr>
<td></td>
<td>Hypertension</td>
<td>1.29 (1.02, 1.63)</td>
</tr>
<tr>
<td></td>
<td>Obesity</td>
<td>1.42 (1.12, 1.80)</td>
</tr>
<tr>
<td></td>
<td>Seizure</td>
<td>2.84 (1.55, 5.25)</td>
</tr>
<tr>
<td></td>
<td>Transient ischemic attack</td>
<td>2.22 (1.26, 3.92)</td>
</tr>
<tr>
<td></td>
<td>Death</td>
<td>1.62 (1.14, 2.30)</td>
</tr>
</tbody>
</table>

*Adjusted for age, gender, race, practice location, starting BMI, and tobacco use.

Source: Copyright: J Community Health © 2006 Springer Science+Business Media, Inc.
Percent of Patients Ever Having a Diagnosis of Each Health Condition, by Primary Disabling Condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Sensory (%)</th>
<th>Trauma (%)</th>
<th>Developmental (%)</th>
<th>Psychiatric (%)</th>
<th>Comparison (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>5.13</td>
<td>9.68</td>
<td>5.92</td>
<td>12.78</td>
<td>9.02</td>
</tr>
<tr>
<td>Asthma</td>
<td>3.42</td>
<td>5.81</td>
<td>4.34</td>
<td>8.04</td>
<td>5.71</td>
</tr>
<tr>
<td>Cancer</td>
<td>11.97</td>
<td>9.03</td>
<td>2.89</td>
<td>10.52</td>
<td>9.37</td>
</tr>
<tr>
<td>CAD</td>
<td>15.38</td>
<td>11.61</td>
<td>2.31</td>
<td>9.90</td>
<td>8.84</td>
</tr>
<tr>
<td>CHF</td>
<td>17.95</td>
<td>5.16</td>
<td>2.60</td>
<td>12.58</td>
<td>5.62</td>
</tr>
<tr>
<td>COPD</td>
<td>11.97</td>
<td>18.71</td>
<td>6.36</td>
<td>20.82</td>
<td>9.51</td>
</tr>
<tr>
<td>Dementia</td>
<td>15.38</td>
<td>18.06</td>
<td>6.07</td>
<td>7.63</td>
<td>3.22</td>
</tr>
<tr>
<td>Depression</td>
<td>21.37</td>
<td>37.42</td>
<td>16.76</td>
<td>29.07</td>
<td>22.72</td>
</tr>
<tr>
<td>Diabetes</td>
<td>31.62</td>
<td>16.13</td>
<td>10.40</td>
<td>24.74</td>
<td>15.76</td>
</tr>
<tr>
<td>Hypertension</td>
<td>40.17</td>
<td>41.94</td>
<td>28.90</td>
<td>57.11</td>
<td>43.95</td>
</tr>
<tr>
<td>Obesity</td>
<td>65.81</td>
<td>67.74</td>
<td>67.49</td>
<td>78.97</td>
<td>72.62</td>
</tr>
<tr>
<td>Seizure</td>
<td>12.82</td>
<td>20.65</td>
<td>27.31</td>
<td>3.71</td>
<td>1.25</td>
</tr>
<tr>
<td>TIA</td>
<td>8.55</td>
<td>2.58</td>
<td>0.29</td>
<td>4.12</td>
<td>1.73</td>
</tr>
<tr>
<td>Death</td>
<td>16.24</td>
<td>7.10</td>
<td>2.76</td>
<td>11.75</td>
<td>6.77</td>
</tr>
</tbody>
</table>

Source: Copyright: J Community Health © 2006 Springer Science+Business Media, Inc.
Variations in Health Conditions Among Disabled Adults in Primary Care: Results

Results:
• Similarities in prevalence for many health conditions among those with and without disability.
• Some conditions with higher prevalence are secondary to primary disability: e.g. depression, seizures, and dementia.
• Earlier age of diagnosis of chronic conditions in the disabled versus the non-disabled.

<table>
<thead>
<tr>
<th>Countries of Studies</th>
<th>Dutch $^a$</th>
<th>Australia $^b$</th>
<th>USA $^c$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Origin of sample</td>
<td>3 institutes</td>
<td>Aging clinic</td>
<td>1 urban &amp; 1 rural clinic</td>
</tr>
<tr>
<td>Sample Size</td>
<td>470</td>
<td>155</td>
<td>692</td>
</tr>
<tr>
<td>Age range at enrollment</td>
<td>50-90</td>
<td>$&gt;$40</td>
<td>30-40 (mean 42)</td>
</tr>
<tr>
<td>Unhealthy Diet (%)</td>
<td>98.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack exercise (%)</td>
<td>68.3</td>
<td>96</td>
<td></td>
</tr>
<tr>
<td>Overweight or obese (%)</td>
<td>70.4</td>
<td>70</td>
<td>67.49</td>
</tr>
<tr>
<td>CVD (%)</td>
<td></td>
<td>5</td>
<td>2.3</td>
</tr>
<tr>
<td>HTN (%)</td>
<td>36.8</td>
<td>18</td>
<td>28.9</td>
</tr>
<tr>
<td>Hypercholesterolemia or elevated cholesterol (%)</td>
<td>31.8</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Elevated glucose or Diabetes (%)</td>
<td>8.7</td>
<td>8</td>
<td>10.4</td>
</tr>
</tbody>
</table>

BMI in Adults with ID:

- Obesity associated with
  - living independently/with family
  - ability to feed/drink unaided
  - being female
  - hypertension
  - Down Syndrome
  - absence of cerebral palsy

- CONCLUSION: Obesity in women was more common in adults with ID than in the general population after controlling for differences in the age distributions between the two populations.

Down Syndrome and Alzheimer’s

- General population – Alzheimer’s Disease (AD) usually diagnosed in the 7th decade (>60 yrs old).
- AD diagnosed in Down Syndrome as early as the 5th decade (>40 yrs old).
- Almost 100% of all Down Syndrome adults (by age 45 or 50) develop the AD brain changes (plaques and tangles).
- 20-40% of those with Down Syndrome will develop a clinical dementia.
## Physical and Mental Health Co-morbidities in Persons with Down Syndrome with and without Alzheimer’s Dementia

<table>
<thead>
<tr>
<th>Co-Morbidity</th>
<th>With Alzheimer’s Disease (%)</th>
<th>Without Alzheimer’s Disease (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>55.5</td>
<td>11.4</td>
<td>0.001</td>
</tr>
<tr>
<td>Lung problems</td>
<td>55.5</td>
<td>8.1</td>
<td>0.0001</td>
</tr>
<tr>
<td>Depressive Illness</td>
<td>38</td>
<td>18.0</td>
<td>0.03</td>
</tr>
<tr>
<td>Arthritis</td>
<td>14</td>
<td>1.6</td>
<td>0.01</td>
</tr>
<tr>
<td>Gastric Disorders</td>
<td>16.9</td>
<td>1.6</td>
<td>0.005</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>88.9</td>
<td>72.1</td>
<td>0.02</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>44.4</td>
<td>21.3</td>
<td>0.006</td>
</tr>
<tr>
<td>Immobility</td>
<td>33.6</td>
<td>3.3</td>
<td>0.0001</td>
</tr>
</tbody>
</table>

Cumulative Incidence of Dementia in DS Individuals by Premorbid Depression

From Leonard L. Magnani, M.D., Ph.D. Access Attitudes and Aging  September 25, 2007
Cholesterol History and Alzheimer’s Disease

- AD is caused, at least in part, by an abnormal accumulation of the beta-amyloid protein in specific brain regions.
- Both the generation and clearance of beta-amyloid are regulated by cholesterol.
- Elevated cholesterol levels increase beta-amyloid in cellular and most animals models of AD.
- Drugs that inhibit cholesterol synthesis may decrease risk for AD in select populations.
Incidence of AD in Downs Syndrome by Hypercholesterolemia History

From Leonard L. Magnani, M.D., Ph.D. Access Attitudes and Aging September 25, 2007
Why is the Aging of the Developmentally Disabled Now an Issue?

- Improved medical interventions
- Increased life expectancy
- Community living and support
- Many of the DD population have
  - new skill sets
  - access to resources to cope with aging changes
  - are outliving the parents who cared for them
  - are having to fend for themselves.
Testimony on Caring for Aging Children with Developmental Disabilities by an Aging Parent

http://www.youtube.com/watch?v=CGC2DXGfmUw
Behavior and Cognition of Persons with Intellectual Disability

- Intelligence and ability typically stay the same.
- ID and aging: ↑difficulty processing, organizing new information, and recalling old information.
- Aging oftentimes slows memory “retrieval”.
- Mental illness (especially depression) - more prevalent in elders with a developmental disability than in the general population.

From Leonard L. Magnani, M.D., Ph.D. Access Attitudes and Aging September 25, 2007
Pilot Study of Oral Health Among Persons with Developmental Disabilities

Objective:
To survey the oral health conditions among Persons with Developmental Disabilities (PDD) in one Regional Center in Los Angeles.

Characteristics of PDD Enrollees in Pilot Study of Oral Health

• The sample consisted of 102 ‘clients’.
• Mean age was 37 years (range 21 to 53 years); 57% were male.
• 46% were African American and 32% were Hispanic.
• 52% lived in group home.
• 80% had less than $10,000 annual income.
• All were mild to moderately mentally retarded.
Results: Oral Health Needs Among Persons with Developmental Disabilities in LA Regional Center

- 13% needed urgent dental care
- 26% unable to access needed dental care in the last year
- Prevalence of tooth pain in the last six months = 25%
- 6 – 7 missing teeth per person
- 26% needed a dental prosthesis

Characteristics of PDD Enrollees in Pilot Study of Oral Health

Oral Health Behaviors

• 24% did not brush daily
• 88% did not floss
• 5% visited a dentist for preventive care

Oral Health of People with Intellectual Disability UK Special Olympics

Mean age = 28 years (range 8–73)

Percentage of SO participants with 21+ natural teeth, no fillings and no untreated decay by age group (n = 981).

Oral Findings in the ID/DD Population

• Periodontal status:
  – Over a 9 year period

  57.4% of lost teeth due to periodontitis

  – Perio problems 2 x > than general population
Oral Findings in the ID/DD Population

- Habits and Compulsions
  - 30% have self-injurious behavior. Bennett K. Florida Atlantic University www.coe.fau.edu/card/Presentations/Self-InjuriousBehavior%20.ppt
Oral Findings in the ID/DD Population

• Malocclusion
  – About 1/3rd had a class II or III occlusion
  – 35% cross-bite
  – 25% crowded incisal conditions
  – 43% vertical overjet of >2mm
  – 14% open bite

Oral Findings in the ID/DD Population

• Caries
  - Prevalence of active decay was 65%
  - Most important factors for caries and extraction related to oral care rather than level of disability.
Comparing the Oral Health & Dental Service Use of Adults with Learning Disabilities Living in Residential Institutions or the Community in the UK

<table>
<thead>
<tr>
<th>Community Living</th>
<th>Residential Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>• n=130 (62%)</td>
<td>• n=79 (38%)</td>
</tr>
<tr>
<td>• Mean age 36.3</td>
<td>• Mean age 43.2</td>
</tr>
<tr>
<td>• Decayed Teeth = 1.6</td>
<td>• Decay = 0.7</td>
</tr>
<tr>
<td>• Missing Teeth = 7.5</td>
<td>• Missing teeth = 10.1</td>
</tr>
<tr>
<td>• Less likely to seek dental care</td>
<td>• More likely to have a regular dentist</td>
</tr>
<tr>
<td>• More likely to go when a problem</td>
<td>• More likely to have care on a schedule</td>
</tr>
<tr>
<td>• Greater unmet oral needs</td>
<td></td>
</tr>
</tbody>
</table>

# Oral Health of Patient with ID: A Systematic Review

## Scientific Quality Rankings
- Maximum 10 points
- 27 papers reviewed
- Only 6/27 had scores of >7

<table>
<thead>
<tr>
<th>Author (country)</th>
<th>Date</th>
<th>Score</th>
<th>Subjects</th>
<th>Controls/comparison group</th>
<th>Measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hinchliffe (England)</td>
<td>1988</td>
<td>9</td>
<td>324 adults with mental retardation (MR)</td>
<td>165 age and gender-matched controls</td>
<td>DMFT, oral cleanliness, gingivitis, periodontal status, dentures</td>
<td>People with MR had poor oral hygiene, similar caries prevalence, more untreated caries, more gingivitis, more periodontal disease, worse OH, more traumatized teeth.</td>
</tr>
<tr>
<td>Sakellari (Greece)</td>
<td>2005</td>
<td>8</td>
<td>70 adolescents and young adults with Down syndrome (DS)</td>
<td>70 people with cerebral palsy, 121 age-matched controls</td>
<td>Probing depth, probing attachment level, bleeding on probing (BOP), hygiene, microbiology</td>
<td>People with DS had worse oral hygiene, more BOP, more severe periodontal destruction, earlier, heavier colonization with periodontal pathogens.</td>
</tr>
<tr>
<td>Zigmond (Israel)</td>
<td>2006</td>
<td>7</td>
<td>30 adults with DS</td>
<td>28 age-matched healthy controls</td>
<td>Plaque scores, BOP, probing depth, gingival recession, clinical attachment level, radiographic bone loss</td>
<td>People with DS had similar oral hygiene and gingival measures but severe periodontal disease. Prevalence, extent, and severity of periodontitis was significantly greater in DS group.</td>
</tr>
<tr>
<td>Cheng (China)</td>
<td>2007</td>
<td>7</td>
<td>65 adults with DS, age 17–42</td>
<td>65 age and gender-matched controls</td>
<td>DFT, plaque index (PI), BOP, pocket depths</td>
<td>People with DS had more plaque, fewer remaining teeth, more dental anomalies, fewer caries but more BOP, more severe periodontal disease, fewer filled teeth, more retained primary teeth.</td>
</tr>
<tr>
<td>Lopez-Perez (Mexico)</td>
<td>2002</td>
<td>7</td>
<td>32 people with DS, age 15–39</td>
<td>32 age and gender-matched controls</td>
<td>Simplified oral hygiene index (SOHI), gingival index (GI) attachment levels</td>
<td>DS group had more severe gingivitis but not periodontitis; greater extent of gingivitis and periodontitis, lower levels of calculus, similar plaque levels.</td>
</tr>
</tbody>
</table>

Anders P. and Davis E. Special Care Dentistry 2010;30(3):110-117.
Age Distribution of ID Patients Seen at the SPC - Ostrow School of Dentistry of USC 2005 - 2010
Receiving Needed Medical Care

Q1100 In the past 12 months, was there a time when you needed medical care but did not get it, or not?

Base: People with disabilities (n=1,001) and People without disabilities (n=788)

Receiving Needed Medical Care Compared to Degree of Disability

People with more severe disabilities are more likely to say that they go without needed medical care than are people with slight disabilities.

- Slight (n=121):
  - Yes: 12%
  - No: 87%
- Moderate (n=310):
  - Yes: 13%
  - No: 87%
- Somewhat Severe (n=347):
  - Yes: 20%
  - No: 80%
- Very Severe (n=203):
  - Yes: 27%
  - No: 71%

• The proper education and intervention of physicians and health care providers can make the difference between this group of patients living life to their greatest opportunity or suffering early mortality and morbidity.

Best Practices for State and Community Oral Health Programs

- Oral Health of Children, Adolescents and Adults with Special Health Care Needs (SHCN)
- Development of a Strategic Framework
- Published by the Association of State and Territorial Dental Directors (ASTDD)

Best Practices for State and Community Oral Health Programs for Individuals with SHCN

• SHCN includes cerebral palsy, cystic fibrosis, sickle cell disease, asthma, diabetes, spina bifida, epilepsy and mental retardation.

• Children with SHCN grow to become adolescents and adults with special health care needs (SHCN) and experience challenges throughout their lifespan.

• Many individuals with SHCN do not have a dental home and may experience significant barriers in obtaining dental services.

Principles Promoted in Best Practices about Oral Health and Individuals with SHCNs

- Maintaining good oral health is a significant issue for individuals with SHCN of all ages.
- Oral health of individuals with SHCN impacts their general health.
- Some individuals with SHCN possess cognitive and motor abilities to maintain oral health and are able to cooperate during dental treatment.
- Others have cognitive deficiencies, physical limitations, and/or behavior problems that compromise self-care and may require additional management for dental care.

What Is Needed for the Future?

FOR THE PATIENT
THE PARENT OR CAREGIVER
THE ORAL HEALTH PROVIDER
THE COMMUNITY?
1- Empower Individuals with SHCNs and Their Parents/Caregivers

<table>
<thead>
<tr>
<th>Strategic Component 1:</th>
<th>Examples of activities:</th>
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</thead>
</table>
| Empower individuals with SHCN and their parents/caregivers and advocate for their oral health | • Improve the oral self-care skills of individuals with SHCN.  
• Improve the oral health knowledge and skills of parents and caregivers in the family home, group homes and institutional settings; motivate them to maintain oral hygiene of individuals with SHCN.  
• Inform individuals with SHCN, parents and caregivers about dental care resources, such as dentists who accept patients with SHCN in their practices.  
• Conduct community- and state-wide studies that highlight oral health needs and access-to-care problems of individuals with SHCN.  
• Acquire meaningful input from families to consider in program planning, implementation and policy development.  
• Promote partnerships and coalitions to advocate oral health improvements for individuals with SHCN. |

### 2- Prepare the Dental Workforce to Serve Individuals with SHCNs

<table>
<thead>
<tr>
<th>Strategic Component 2:</th>
<th>Examples of activities:</th>
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</table>
| Prepare the dental workforce to serve individuals with SHCN | - Offer didactic, interdisciplinary and clinical education in the care of individuals with SHCN to all oral health professionals during their professional training.  
- Include more “special needs” content in postgraduate training programs such as GPR, AEGD and pediatric residencies.  
- Provide more postgraduate fellowships in special care dentistry.  
- Increase the availability of and stimulate the demand for continuing education on special care dentistry. |

3- Make Financing System More Responsive to Individuals with SHCNs

<table>
<thead>
<tr>
<th>Strategic Component 3: Make the financing system more responsive to individuals with SHCN</th>
<th>Examples of activities:</th>
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<tbody>
<tr>
<td>Assure dental insurance coverage for individuals with SHCN.</td>
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<tr>
<td>Extend coverage of oral health services in Medicaid, SCHIP and commercial plans for special oral health services that are “medically necessary.”</td>
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</tr>
<tr>
<td>Improve reimbursement rates for oral health services provided to individuals with SHCN.</td>
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<tr>
<td>Create innovative systems of care utilizing the Medicaid waiver process, e.g., dental clinics specializing in the care of individuals with SHCN.</td>
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4 – Organize Community Resources to Increase Access to Dental Care

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<tr>
<th>Strategic Component 4:</th>
<th>Examples of activities:</th>
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| Organize community resources to increase access to dental care for individuals with SHCN | • Establish dental case management programs to assist individuals with SHCN and their families.  
• Develop outreach programs for individuals with SHCN and their families that identify oral health problems at an early stage and facilitate referral for care.  
• Establish community-based and school-based dental clinics able to provide services to individuals with SHCN.  
• Increase the availability of hospital dental OR services for individuals with SHCN.  
• Preserve dental clinics in state institutions and expand their services for people with MR/DD residing in the institution and in the community.  
• Train and encourage medical professionals to identify oral health problems of their patients with SHCN, make necessary dental referrals, and follow up on needed dental care. |

Limitations of the Intellectually Disabled That Must Be Considered

- Community environments typical of the individual’s age, peers and culture
- Co-existing strengths
- Cultural and linguistic diversity
- Differences in communication, sensory, motor and behavioral factors

AAMR, 2002
Resulting Programs Should

- Allow for personalization of supports over a sustained period
- Develop a profile of needed supports
- Help to improve the life functioning of the person

AAMR, 2002
People with disabilities say they are much less satisfied with life than people who do not have disabilities.

Thank You!