Community Task Force on Oral Health for Individuals with Developmental Disabilities

Consumer Perceptions and Satisfaction Workgroup

Steering Committee Meeting
May 23, 2012
Consumer Perceptions and Satisfaction

**Purpose**: To describe the perceptions and satisfaction with oral health status and available resources for individuals with developmental disabilities.

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Preliminary Results

• Total Responses: 607
  – Survey Monkey= 370; Hard Copy= 237

Q: Who is Completing this Survey?

- Individual with a Disability: 7.91% (48)
- Parent: 35.58% (216)
- Legal Guardian: 2.64% (16)
- Residential Care Provider: 24.05% (146)
- Other: 29.82% (181)
Perception of Oral Health

Q.2. Perception of Oral Health

- Please rate your dental health:
  - Excellent: 11.2%
  - Good: 35.9%
  - Fair: 39.5%
  - Poor: 13.4%
  - n= 529

- Please rate the appearance of your teeth and gums:
  - Excellent: 11.2%
  - Good: 39.5%
  - Fair: 13.4%
  - Poor: 13.4%
  - n= 525

- Please rate the effect of your oral health on social relationships:
  - Excellent: 11.2%
  - Good: 39.5%
  - Fair: 13.4%
  - Poor: 13.4%
  - n= 507
Perception of Oral Health

Q.3. Perception of Oral Health

- Have you experienced dental pain when receiving dental services:
  - Significant: 12.6%
  - Moderate: 41.9%
  - Little: 21.2%
  - None: 24.3%

- Have you experienced fear when receiving dental services:
  - Significant: 28.9%
  - Moderate: 24.3%
  - Little: 21.2%
  - None: 12.6%

- Have you experienced anxiety when receiving dental services:
  - Significant: 32.2%
  - Moderate: 28.9%
  - Little: 21.2%
  - None: 12.6%

n= 515  n= 519  n= 521
Q. 23. Oral or dental health is important for overall health.

- Strongly Agree: 32.8%
- Agree: 37.2%
- Indifferent: 13.2%
- Disagree: 1.9%
- Strongly disagree: 14.8%

n = 521
Satisfaction with Dental Services

Q. 4. Satisfaction with Dental Services

- Dental service provider options: 40.7%
- Location of dental service providers: 26.8%
- Accessibility of dental office: 22.6%
- Ease of scheduling appointments: 6.3%
- Waiting time to get an initial or follow-up appointment: 40.7%
- Time spent in waiting area: 26.8%
- Comfort of waiting area: 22.6%
- Time spent in dental chair: 6.3%
- Comfort of dental chair: n= 519-526
Type of Condition

- Other: 136
- Spina bifida: 5
- Cerebral palsy: 70
- Down syndrome: 50
- Intellectual disability: 277
- Autism spectrum disorders: 160
Demographics

Gender

- Males: 212,41%
- Females: 310,59%

Race/Ethnicity

- White: 54%
- Black/African American: 21.6%
- Hispanic/Latino: 20.9%
- Asian/Pacific Islander: 6.2%
- Native American/Alaskan: 1.5%
- Other: 0.8%

Education

- Completed Graduate School: 30.2%
- Completed College: 162
- Completed High School: 62.4%
- Some Graduate School: 2
- Some College: 8
- Some High School: 18
- Other: 12

Age: 3 - 88 years
Demographics

Q. 12 Primary Method of Payment for Dental Care

- Medicaid: 78.4%
- Other: 15.5%
- Child/Family Health Plus: 2.6%
- Out-of-pocket/Self pay: 16.7%
- Medicare: 19.3%
- Private Insurance: 16.3%

n= 502

Q. 17. Annual household income

- < 15,000: 29.5%
- 15,000 - < 30,000: 16.3%
- 30,000 - < 50,000: 19.3%
- ≥ 50,000: 16.7%
- Don't know/Not sure/Not applicable: 15.5%
- I prefer not to answer: 2.6%

n= 502
Q. 15. What is your living situation?

- **With parent/guardian**: 49.5%
- **In foster care**: 17.3%
- **Independent living**: 29%

n = 525
Q. 18. When was your last dental visit?

- 64.5% within last 6 months
- 19.4% between 6 months and 1 yr
- 7.5% between 1 and 2 yrs
- 5.4% more than 2 yrs
- 2.1% no visit
- 1.2% don’t remember

n= 502

- Only if trouble with teeth: 9.2%
- Occasional dental visit: 19.7%
- Regular dental visit (every 6 months): 71.1%
Q. 20. If you have not received regular dental care in the past, what are some reasons?
Q.22 Was there any time during the last 12 months that, in your opinion, you personally needed a dental exam or treatment, or had a dental problem but did not receive care?

88.5% No
11.5% Yes

n= 516
Q. 21. I always feel anxious or nervous about going to the dentist.

- Definitely feel like that: 32.0%
- To some extent: 42.6%
- Not at all: 25.4%

n = 517
Demographics of Caregiver

Gender of Caregiver

- Males: 44.14%
- Females: 274.86%

Q. 28 Race/Ethnicity of caregiver

- White: 100.0%
- Black/African American: 50.0%
- Hispanic/Latino: 10.0%
- Asian/Pacific Islander: 5.0%
- Native American/Alaskan: 5.0%
- Other: 5.0%
Demographics of Caregiver

Q. 29. Caregiver's annual household income

- < 15,000: 29.6%
- 15,000 - < 30,000: 12.7%
- 30,000 - < 50,000: 10.7%
- ≥ 50,000: 30.6%
- Don't know/Not sure/Not applicable: 11.7%

Q. 26. Education level of caregiver

- Some high school: 22.3%
- Some college: 19.3%
- Completed high school: 31.6%
- Completed college: 11.7%
- Completed graduate school: 4.6%
- Other: 10.7%

Source: UNIVERSITY of ROCHESTER MEDICAL CENTER | EASTMAN INSTITUTE FOR ORAL HEALTH
Survey Comments

- Provider Attitude/Training/Quality of Care
- Accessibility
- Insurance or Payment
- Facilities
- Anxiety
- Wait Times
- Positives
Focus Groups

3 focus group sessions:
• Tuesday 4/17/12 at 10am Al Sigl
• Saturday 4/21/12 at 10am SRB
• Wednesday 4/25/12 at 6pm SRB

Tape recorded and transcribed
Focus Groups

Session Questions

1) What are your thoughts about oral hygiene?
2) Oral hygiene, whose responsibility is it?
3) Describe the ideal dental care visit; what would it look like?
4) In closing, if there was one thing you would want included in the summary report, what would it be?
Focus Groups

• Participants:
  – 7 parents
  – 1 sibling
  – 0 persons with IDD

• The preliminary results underscore the need for more supports for people with IDD

• Major themes:
  – Communication
  – Disability-specific concerns
  – Service System Issues
  – Health Insurance and financial issues
  – Responsibility for oral hygiene: everyone
  – Caregiver challenges
Preliminary Suggestions

• Patient-centered care:
  – “Get to know my child” form prior to dental visit;
  – Communication between all medical and dental providers
  – “Layered” visit to reduce anxiety

• Education - continuing education & training for:
  – oral health care providers and staff;
  – group home care providers and staff;
  – care givers

• Community Resources:
  – Increase number of providers who treat patients with DD;
  – Create dental provider directory as referral resource for DD patients;
  – Promote educational materials/public service announcements to increase awareness of importance of oral health & early intervention, with a focus on prevention
Next Steps

• Further analysis of quantitative data from survey responses

• Review findings from quantitative (survey) and qualitative (focus group) analyses

• Identify actionable recommendations based on findings
Thank You!