Oral Health for People with Special Needs – Fact Sheets for Caregivers and Professionals

1. This series of Oral Health for People with Disabilities aims at promoting oral disease prevention at home, and increasing access to oral health care as well as community awareness. What makes this series successful is that it focuses on children and adults with special needs with MINOR and MODERATE chronic conditions. This population group seeks care in hospitals dental clinics but they could be comfortably treated in community dental offices, avoiding the unnecessary high costs of hospital care. Another reason for the success of this project is that it addresses the concerns raised by different parts of the health care system, as described below. This work was possible due to a 4-year federal funding through HRSA TOHSS Grant #07-039.

The literature shows that there are overall 17% of children with special needs nationwide. Children with special needs are more likely to have dental disease and low access to dental care than children without special needs. Parents of children with special needs say that dental care is the first unmet health care need for their kids. Children with severe chronic conditions need to seek dental care in tertiary care centers (hospitals), while children with minor and moderate chronic conditions (which represent the majority of children with special needs) have difficulty in finding dental care in their communities. Based on focus groups supported by this grant, it was found out that:

- Dental professionals do not feel they have received enough training to serve this population group; they also have concerns about reimbursement and about the transition to adulthood.
- Medical professionals say that they do not understand enough of oral health to make a quick assessment, provide preventive advice and make dental referrals for children with special needs.
- Caregivers say that oral health care becomes a non-priority given the high number of medical needs of their children and the difficulty of accessing dental care. They also say that it is hard to provide oral health care at home.
- Insurance companies, parents and health professionals say that communication among them can be frustrating and lead to misunderstandings.
- Community groups are not aware of the oral health needs of people with special needs.

2. By working with the University of Washington School of Dentistry DECOD Program, a national expert on people with special needs, extensive literature review and consultation with and review by university faculty in medical and dental schools, these fact sheets were developed. The fact sheets are individually tailored to 14 conditions for children and 16 for adults. Each chronic condition’s fact sheet has three versions, tailored to the different users: for dental professionals, for medical professionals, and for caregivers. The medical and dental professional fact sheets provide a quick overview of these conditions, drugs frequently used by individuals with these conditions and the impact medications may have on oral health. The fact sheets include additional suggestions for working with this population to improve clinical outcomes, increase professional comfort and engage parents and caregivers in the oral health of these individuals. The fact sheets for caregivers provide helpful hints on how to provide oral health care at home and how to make a dental visit a successful experience. The fact sheets cover the following conditions:

- Attention Deficit Disorders and Attention Deficit Hyperactivity Disorder
- Anxiety and Depression
- Autism Spectrum Disorders
Cerebral Palsy  
Cleft Lip and Palate  
Congenital Cardiac Disorders  
Diabetes Type 1 & 2  
Down Syndrome  
Eating Disorders: Anorexia, Bulimia  
Epilepsy  
Hearing Impaired  
HIV  
Intellectual Disability  
Respiratory Disorders: Asthma and Allergies  
Traumatic Brain Injury

Other information available in this series include:
- Guidance sheets for caregivers (also in Spanish) and for the dental and medical professionals.
- Child abuse guidance for dental professionals.
- Fact sheet on insurance issues (coming soon)
- Fact sheet for community groups (coming soon)

3. These materials are available free of charge through downloading at the University of Washington School of Dentistry. The fact sheets will also be available online for continuing education credits at University of Washington Continuing Dental Education.

4. Fact sheets have been praised for being reader friendly, brief and still comprehensive. Dental and medical professionals can use them at their convenience. There is also the opportunity for professionals to get CE credits. The overall benefit of this project is that it educates and trains different components of the health system, decreasing miscommunication and frustration, and leading to a more effective way to care for people with special needs. More specific benefits include:
   - Health professionals receive additional clinical information and become more knowledgeable and confident in serving people with special needs with MINOR to MODERATE chronic conditions in their dental offices. With this increase in knowledge, it is expected these dental professionals will more likely fill a gap of underserved individuals and provide regular and ongoing treatment.
   - Caregivers, who often have so many medical needs to attend to, have tailored information on how to provide oral hygiene at home, therefore preventing dental disease, as well as how to communicate with dental offices and insurers in a more effective manner.
   - Insurance groups learn about the clinical issues related to oral health care for people with special needs and see improved communication with caregivers and health professionals.
   - Community groups become more aware of health issues related to people with special needs and can use such information to enhance quality of life for this population group.

5. These materials are being used nationwide. University of WA is including these materials in their curriculum, as well as other dental and dental hygiene programs. Safety net dental clinics have shown interest in doing this CDE training online for their dental professionals. Parent organizations and community groups are increasingly discussing oral health as part of the general health needs of people with special needs.

Lessons Learned:

1. It is essential to disseminate these materials to those interested in improving the quality of life of people with special needs, including caregivers, professionals, insurers, and community groups. This is a first step towards addressing the different needs of these different parts of the health system. Other steps will be needed to enhance the impact obtained through this work.
2. It will be also important to update the clinical information contained in the fact sheets and guidance. University graduate projects may be a great opportunity to do this updating.
3. Please let us know if you are using these fact sheets in your work.
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