

# Policy on Transitioning from a Pediatric-centered to an Adult-centered Dental Home for Individuals with Special Health Care Needs

## Review Council

Council on Clinical Affairs

## Revised

2016

### Purpose

The American Academy of Pediatric Dentistry (AAPD) recognizes the importance of transitioning patients with special health care needs (SHCN) to an adult dental home as they reach the age of majority. Finding a dental home<sup>1</sup> to address their special circumstances while providing all aspects of oral care in a comprehensive, continuously accessible, coordinated, and family-centered manner may be a challenge. This policy addresses transition of young adult patients with SHCN and identifies barriers that may challenge delivery of oral health care to this population.

### Methods

This policy was originally developed by the Council on Clinical Affairs and adopted in 2011. This document is an update of the original version. The revision used electronic database and hand searches of dental and medical literature, using the terms: special needs, disabled patients, handicapped patients, adolescent development, adolescent health, special health care needs AND health care transition, oral health; fields: all; limits: within the last 10 years, humans, English, birth through age 18, young adult: 19-24 years. Additionally, Websites for the American Dental Association, American Medical Association, American Academy of Pediatric Dentistry, Agency for Healthcare Research and Quality, Special Care Dentistry Association, and International Association for Disability and Oral Health were reviewed. Expert opinions and best current practices were relied upon when clinical evidence was not available.

### Background

AAPD is aware of the challenges that SHCN patients and their families encounter when seeking oral health care. As the prevalence of SHCN children has been increasing over the past decades with advances in medical technology, the number of young adults with chronic health conditions also has increased.<sup>2,3</sup> It has been estimated that approximately 25 percent of the 18 million U.S. young adults ages 18 to 21 who should be transitioning to adult-centered care are affected by at least one chronic health condition.<sup>4</sup> Each year in the U.S.,

750,000 adolescents with SHCN cross into adulthood, with only 40 percent receiving attention to core transition issues.<sup>2,5</sup>

Transitions are part of normal, healthy development and occur across the life span. Health care transition for older adolescents with SHCN is a dynamic process that seeks to meet their individual needs. The goal is to maximize lifelong functioning and potential through uninterrupted provision of high-quality, developmentally-appropriate health care as the individual moves from adolescence into adulthood. The cornerstones of patient-centered health care are flexibility, responsiveness, continuity, comprehensiveness, and coordination.<sup>6</sup>

**Transitioning patients with SHCN.** Facilitating health care transition for SHCN patients has received national attention from other organizations recognizing the need to support the process.<sup>4,7,8</sup> The medical community, specifically, and the broader health care community (including dentistry) have yet to ensure that young people with SHCN who are the most dependent on coordinated health care services are able to make the transition to the adult health care system and still receive the services that they need.<sup>9,10</sup> Only one-third of pediatricians report making adequate referrals to adult physicians and fewer than 15 percent provide appropriate educational materials to adolescents and their parents. This is of concern for dental patients because adolescents who do not receive medical transitions are less likely to receive dental transitions.<sup>11</sup> Additional factors associated with limited access to care during adulthood transitioning include living in poverty and being a minority.<sup>12-14</sup> There is evidence that a proper handoff, including clear direct or indirect communication between providers, reduces medical errors during the transition.<sup>9</sup> This transitioning period is potentially stressful for parents and adolescents or young adults with SHCN, and there is a paucity of resources for acquiring adulthood healthcare.<sup>15-17</sup>

To improve health care transition for adolescents and young adults with chronic conditions, a policy statement was established by a number of medical organizations.<sup>12</sup> The policy statement articulated six critical steps to ensuring the successful transition to adult-oriented care. They are:

1. To ensure that all young people with special health care needs have a health care provider who takes specific responsibility for transition in the broader context of care coordination and health care planning.
2. To identify the core competencies required by health care providers to render developmentally appropriate health care and health care transition, and ensure that the skills are taught to primary care providers and are an integral component of their certification requirements.
3. To develop a portable, accessible, medical summary to facilitate the smooth collaboration and transfer of care among and between health care professionals.
4. To develop an up-to-date detailed written transition plan, in collaboration with young people and their families.
5. To ensure that the same standards for primary and preventive health care are applied to young people with chronic conditions as to their peers.
6. To ensure that affordable, comprehensive, continuous health insurance is available to young people with chronic health conditions throughout adolescence and into adulthood.<sup>18</sup>

Although these steps represent a medical perspective, they may be applied to oral health care as well.

It is important to educate and prepare the patient and parent on the value of transitioning to a dentist who is knowledgeable in adult oral health needs. At a time agreed upon by the parent, patient, and pediatric dentist, the patient should be transitioned to a dentist knowledgeable and comfortable with managing the patient's specific health care needs. In cases where this is not possible or desired, the dental home can remain with the pediatric dentist and referrals for specialized dental care should be recommended when needed.<sup>18</sup>

Discussion about transition can begin early, although the transfer of care may not take place for many years.<sup>3</sup> There is evidence in support of initiating a transition plan between the 14 and 16 years of age.<sup>19</sup> Anecdotal evidence suggests that transition planning may be happening even earlier.<sup>6</sup>

**Barriers in transitioning patients with SHCN.** Dentistry has been found to be the most common category of unmet health care for children with special needs.<sup>20</sup> Only 10 percent of surveyed general dentists reported that they treat patients with SHCN often or very often, while 70 percent reported that they rarely or never treat patients with SHCN.<sup>21</sup> Pediatric dentists appear more likely to provide dental care for this population as evidenced by a survey of AAPD members which reported that 95 percent routinely treat patients with SHCN.<sup>22</sup>

According to the 2011/2012 National Survey of Children with Special Care Needs, there are approximately 14.6 million children with SHCN under 17 years of age (representing 19.8 percent of all U.S. children).<sup>23</sup> The U.S. has approximately 6000 pediatric dentists.<sup>24</sup> The relatively small number and distribution of pediatric dentists mean that broader involvement by general dentists is necessary to address access to care issues, especially transition of patients with SHCN.<sup>25</sup> When patients

reach adulthood, their oral health care needs may go beyond the scope of the pediatric dentist's expertise. Even if a patient is best served by maintaining a dental home with a pediatric dentist, he/she may require additional dental providers to manage some aspects of his/her oral health care. It may not be in the young adult's best interest to be treated solely in a pediatric facility.<sup>26</sup>

Oral health care for adults with special needs is often difficult to access because of a lack of trained providers.<sup>3,25</sup> A recent survey revealed that most pediatric dentists help patients with SHCN transition into adult care, but the principal barrier is the availability of general dentists and specialists willing to accept these patients.<sup>27</sup> A 2005 survey of senior dental students noted that the provision of oral health care to patients with special needs was among the top four topics in which they were least prepared.<sup>28</sup> This self-perceived lack of preparation of future dentists bodes poorly for effective transitioning of adult SHCN patients.

Addressing the manpower issue is of utmost importance. Training and instruction for health care providers can be obtained through post-doctoral educational courses. Programs such as general practice residencies and advanced education in general dentistry provide opportunity for additional medical, behavior guidance, and restorative training needed to treat patients with SHCN. The Special Care Dentistry Association Fellowship and Diplomate programs and Academy of General Dentistry's Mastership program also may provide opportunities to increase the workforce.<sup>29-31</sup>

Most patients with special needs can receive primary oral health care in traditional settings utilizing clinicians and support staff trained in accommodating these individuals. Others require treatment by clinicians with more advanced training in special facilities.<sup>28</sup> Some pediatric hospitals may enforce age restrictions that can create a barrier to care for patients who have reached the age of majority.<sup>16</sup> Hospitals frequently require that dentists eligible for medical staff membership be board certified, thus making it difficult for general dentists to obtain hospital privileges. While surgery centers abound, these may not be the preferred setting to treat medically compromised patients.

Young adults may be discontinued from their parents' insurance, providing a financial barrier to care. Additional barriers to dental transition include low socioeconomic background and insufficient health insurance benefits.<sup>11</sup>

For patients with special needs, overall health care involves intensive and ongoing medical supervision and coordination between medical and dental care. The integration of dentistry within the medical care system presents a series of logistical challenges.<sup>32</sup> There is a lack of special programs or alternative care delivery arrangements (e.g., mobile dental programs, nursing home, group home facilities) to complement the care provided through private practices to address access issues for patients with SHCN.<sup>33</sup>

The medical home<sup>34</sup> reflects recognition that care is best served by having a central point of contact for ongoing primary

care and coordination of care when delivered by a multitude of health care providers and support service providers. The dental home<sup>1</sup> closely parallels the essential elements of the medical home as they relate to dental care.<sup>33</sup>

Linkages between patients' medical and dental homes, however, often are not established as formally as those among medical care providers, frequently resulting in inattention to dental services for patients with SHCN.<sup>35</sup> Efforts to establish stronger relationships between medical and dental homes are an important endeavor.<sup>36,37</sup>

The most efficient but least common arrangement of care for patients with SHCN is a single institution having providers from both disciplines (typically a hospital or regional care center).<sup>32</sup> Transitioning may become less of an issue in these facilities; however, those with comprehensive dental clinics are limited in number and spread unevenly across the country.

### Policy statement

A coordinated transition from a pediatric-centered to an adult-centered dental home is critical for extending the level of oral health and health trajectory established during childhood.

The AAPD encourages:

- Expansion of the medical and dental home across the life-span of a patient, especially to enable successful transition of the adolescent with SHCN.
- Partnerships with other organizations to prepare general dentists to accommodate and provide primary health care for these patients in the usual dental setting.
- Development of special programs or alternative care delivery arrangements (e.g., mobile dental programs, nursing home, group home facilities) to complement the care provided through private practices to address issues for patients with SHCN.
- Utilization of the six critical steps to maximize seamless health care transition for the adolescent dental patient with special needs. These steps provide a framework to organize and prepare the dentist, patient, and patient's family for the transition process.
- Provision of financial assistance for dental treatment for adults with SHCN by local, state, and federal programs.
- Emphasis on the education of dental pre-doctoral students in treating SHCN patients.

### References

1. American Academy of Pediatric Dentistry. Definition of dental home. *Pediatric Dent* 2016;38(special issue):12.
2. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics* 2013;131(6):1090-7.
3. Blum RW. Transition to adult care: Setting the stage. *J Adolesc Health* 1995;17(1):3-5.

4. McPheeters M, Davis AM, Taylor JL, Brown RF, Potter SA, Epstein RA Jr. Transition Care for Children with Special Health Needs. Technical Brief No. 15 (Prepared by the Vanderbilt University Evidence-based Practice Center under Contract No. 290-2012-00009-I). AHRQ Publication No.14-EHC027-EF. Rockville, MD: Agency for Healthcare Research and Quality. June 2014. Available at: "<https://www.effectivehealthcare.ahrq.gov/ehc/products/546/1920/children-special-needs-transition-report-140617.pdf>". Accessed June 29, 2016.
5. Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics* 2005;115(6):1607-12.
6. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128(1):182-200.
7. Koop CE. Executive summary. In: McGrab P, ed. *Growing Up and Getting Medical Care: Youth with Special Health Care Needs*. Jekyll Island, Ga.: U.S. Public Health Service; 1989.
8. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegle DM; Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: Position paper for the Society for Adolescent Medicine. *J of Adolesc Health* 2003;33(4):309-10.
9. Starmer AJ, Spector ND, Srivastava R, et al. Changes in medical errors after implementation of a handoff program. *N Engl J Med* 2014;372(5):490-1.
10. Blum RW. Improving transition for adolescents with special health care needs from pediatric to adult-centered care. *Pediatrics* 2002;110(6 Pt 2):1301-3.
11. Chi DL. Medical care transition planning and dental care use for youth with special health care needs during the transition from adolescence to young adulthood: A preliminary explanatory model. *Matern Child Health J* 2014;18(4):778-88.
12. Amaria K, Stinson J, Cullen-Dean G, Sappleton K, Kaufman M. Tools for addressing systems issues in transition. *Healthc Q* 2011;14(Spec No 3):72-6.
13. Andemariam B, Owarish-Gross J, Grady J, Boruchov D, Thrall RS, Hagstrom JN. Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. *Pediatr Blood Cancer* 2014;61(4):697-701.
14. Annunziato RA, Shemesh E. Tackling the spectrum of transition: What can be done in pediatric settings? *Pediatr Transplant* 2010;14(7):820-2.
15. Arango P. Family-centered care. *Acad Pediatr* 2011;11(2):97-9.
16. Cruz S, Neff J, Chi DL. Transitioning from pediatric care to adult care for adolescents with special health care needs: Adolescent and parent perspectives (Part 1). *Pediatr Dent* 2015;37(5):442-6.

17. Bayarsaikhan Z, Cruz S, Neff J, Chi DL. Transitioning from pediatric care to adult care for adolescents with special health care needs: Dentist perspectives (Part 2). *Pediatr Dent* 2015;37(5):447-51.
18. American Academy of Pediatric Dentistry. Guideline on management of dental patients with special health care needs. *Pediatr Dent* 2016;38(special issue):171-6.
19. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *J Adolesc Health* 2003;32(3):225-33.
20. Newacheck PW, Hung YY, Wright KK. Racial and ethnic disparities in access to care for children with special health-care needs. *Ambul Pediatr* 2002;2(4):247-54.
21. Casamassimo PS, Seale NS, Ruehs K. General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. *J Dent Educ* 2004;68(1):23-5.
22. Nowak AJ. Patients with special health care needs in pediatric dental practices. *Pediatr Dent* 2002;24(3):227-8.
23. Child and Adolescent Health Measurement Initiative (2012). Who Are Children with Special Health Care Needs (CSHCN). Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Dept of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Revised 4/2/12. Available at: "[http://www.cahmi.org/wp-content/uploads/2014/06/CSHCNS-whoarecshcn\\_revised\\_07b-pdf.pdf](http://www.cahmi.org/wp-content/uploads/2014/06/CSHCNS-whoarecshcn_revised_07b-pdf.pdf)". Accessed June 29, 2016.
24. American Academy of Pediatric Dentistry. Membership statistics. Available at: "<http://www.aapd.org/about/stats/>". Accessed June 30, 2016.
25. American Academy of Pediatric Dentistry. Symposium on lifetime oral health care for patients with special needs. *Pediatr Dent* 2007;29(2):92-152.
26. Woldorf JW. Transitioning adolescents with special health care needs: Potential barriers and ethical conflicts. *J Spec Pediatr Nurs* 2007;12(1):53-5.
27. Nowak AJ, Casamassimo PS, Slayton RL. Facilitating the transition of patients with special health care needs from pediatric to adult oral health care. *J Am Dent Assoc* 2010; 141(11):1351-6.
28. Chmar J, Weaver R, Valachovic R. Annual ADEA survey of dental school seniors: 2005 graduating class. *J Dent Educ* 2006;70(3):315-39.
29. Special Care Dentistry. Fellowship in Special Care Dentistry. Available at: "<http://www.scdonline.org/?page=Fellowship>". Accessed June 29, 2016.
30. Special Care Dentistry. Diplomate in Special Care Dentistry. Available at: "<https://scda.site-ym.com/?page=Diplomate>". Accessed June 29, 2016.
31. Academy of General Dentistry. Mastership award guidelines. Available at: "<http://www.agd.org/education-events/examawardsrecognition/mastership-award.aspx>". Accessed June 29, 2016.
32. Edelstein BL. Conceptual frameworks or understanding system capacity in the care of people with special health care needs. *Pediatr Dent* 2007;29(2):108-16.
33. Crall JJ. Improving oral health for individuals with special health care needs. *Pediatr Dent* 2007;29(2):98-104.
34. American Academy of Pediatrics. The medical home. *Pediatrics* 2002;110(1Pt1):184-6.
35. Slavkin HC, Baum BJ. Relationship of dental and oral pathology to systemic illness. *J Am Med Assoc* 2000;284(10):1215-7.
36. Lewis C, Robertson AS, Phelps S. Unmet dental care needs among children with special health care needs: Implications for medical home. *Pediatrics* 2005;116(3): 426-31.
37. American Academy of Pediatric Dentistry. Record transfer form. *Pediatr Dent* 2016;38(special issue):445.