

# Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care

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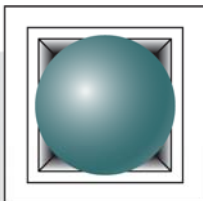
The transition from pediatric to adult health care is a significant issue facing all adolescents, but it is of critical concern to the 17% of adolescents with special health care needs.<sup>1</sup> To make this transition smooth, these young people need assistance over a period of time to assume their new role as informed health care consumers. They also need developmentally appropriate support to understand and manage their condition and to negotiate the changes when they move from pediatric to adult health care systems.

The importance of a planned transition to adult care was recognized by the Department of Health and Human Services' Healthy People 2010, a health promotion and disease prevention agenda.<sup>2</sup> One of its national objectives calls for all youth with special needs to receive services necessary to transition from pediatric to adult health care.<sup>3</sup> In 2002, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) issued a joint statement that defined specific steps for ensuring an effective transition. These include having a primary care provider with responsibility for transition planning, incorporating the necessary knowledge and

skills to provide developmentally appropriate health care transition services, maintaining an up-to-date portable medical summary, creating a written health care transition plan by age 14, implementing recommended preventive service guidelines, and ensuring continuous health insurance coverage.<sup>4</sup> In 2003, the Society for Adolescent Medicine released a position paper endorsing this consensus statement.<sup>5</sup>

Despite consensus, new national data reveal major gaps in implementation. According to the National Survey of Children with Special Health Care Needs, fewer than half of parents who have an adolescent with a special health care need report that their adolescent's doctor or other health care provider talked about meeting health care needs in adulthood. In fact, as many as three out of five parents with adolescents who have special needs reported not receiving the services necessary to make appropriate transitions to adult health care.<sup>6</sup>

Until now, little has been known about how pediatricians incorporate transition support into the ongoing care of their adolescent patients with special health care needs. Existing studies have been based on small samples of pediatricians.<sup>7 8</sup> This fact sheet presents new



nationally representative data on transition services provided by pediatricians.

### Methodology

Data for this fact sheet were obtained from the American Academy of Pediatrics (AAP) Periodic Survey of Fellows #71, conducted in 2008. This AAP survey, which included a broad set of questions on adolescent health care, was sent to a random sample of 1,605 U.S. non-retired members. Data presented here are based on 628 respondents who provide health supervision to patients over 12 years of age. The survey achieved a 64% response rate.

This fact sheet presents current information on pediatricians' perspectives regarding the recommended age to begin planning for transition and describes the range of transition services offered by pediatric practices to adolescents with special health care needs. It also identifies the economic and non-economic barriers that pediatric practices face in providing transition support services and presents options for improving pediatric practice training, financing of transition services, adult physician availability, and consumer and parent education.

### Recommended Age for Transition Planning

Most pediatricians think that transition planning for all adolescents, including those with special health care needs, should begin late in adolescence. In fact, almost two-thirds of pediatricians responded that transition planning for adolescents with special needs should begin between ages 18 and 20, as shown in Table 1. Only a minority think that planning should start earlier, at 14 or younger, as called for in the joint consensus statement. There is little difference among pediatricians in their recommended age for transition planning for adolescent patients with or without special needs.

**TABLE 1. Age at Which Pediatricians Think Transition Planning Should Begin**

Ages	For Adolescents with Special Needs	For Adolescents without Special Needs*
<12 years	3%	2%
12-14 years	6	6
15-17 years	25	26
18-20 years	62	65
Don't know	4	2

\* Totals do not add to 100% because of rounding.

### Transition Support Services Offered in Pediatric Practices

Most pediatric practices do not routinely offer the transition support services that have been identified as critical for ensuring a successful transition to adult-oriented care to most of their adolescent patients who have special needs. In addition, only 11% of pediatric practices have a dedicated staff person with responsibility for coordinating transition planning for this population.

As shown in Table 2, fewer than half of pediatricians report making referrals to specific adult primary and specialty physicians to assist most or nearly all of their adolescent patients who have special health care needs, and about a third report making these referrals for some of these patients. The survey findings also show that only a third of pediatricians discuss consent and confidentiality issues with nearly all of their adolescents who have special needs prior to age 18, and just over a quarter discuss these issues with some of this population. A similar proportion -- about a third -- assist most of their adolescents with special needs by providing medical documentation for SSI and other program eligibility, while about a third assist some of these patients. This is critical as older adolescents and young adults need to qualify for new services.

**TABLE 2. Transition Support Services Offered in Pediatric Practices to Adolescents with Special Needs**

Transition Services	For Nearly All or Most	For Some
Assistance with referral to specific family or internal medicine physicians	47%	33%
Assistance with referral to specific adult specialists	45	32
Discussion of consent and confidentiality issues prior to age 18	33	27
Assistance with medical documentation for program eligibility (e.g., SSI, vocational rehabilitation, college)	32	34
Assistance in creating a portable medical summary	27	26
Education and consultative support to family or internal medicine physicians	23	30
Assistance with identifying insurance options after age 18	19	22
Assistance in creating an individualized health care transition plan	12	26
Provision of educational packet or handouts to adolescents/parents	11	14

Just over a quarter of pediatric practices help nearly all of their adolescent patients who have special needs by assisting in creating a portable medical summary, and about the same proportion provide this service to some of their adolescent patients. The AAP survey also found that less than a quarter of pediatricians provide education and consultation support to adult physicians for most of their adolescents with special needs, and almost a third do so for some of these patients.

When asked about assistance with the identification of insurance options, the development of an individualized health care transition plan, and the provision of educational materials, fewer than a fifth of pediatric practices report offering these services to nearly all or most of their adolescent patients who have special health care needs, and about a quarter or less offer these services to some of these patients.

**Barriers Impeding Transition Support**

Pediatricians report numerous barriers that affect the transition support services that they are able to offer adolescents with special health care needs. Among the most frequently named “major” barriers are shortages of available primary and specialty adult providers, lack of reimbursement and time for transition services, and inadequate information or connections to community support services, as shown in Table 3. Among the most commonly cited barriers -- that is, barriers identified either as a major barrier or somewhat of a barrier -- were difficulties in breaking the bond between pediatricians and adolescents and their parents, the lack of knowledge about or linkages to community resources that support older adolescents, fragmentation of primary and specialty adult health care, and adolescents’ lack of knowledge about their own health condition or skills to self-advocate during physician visits.

With respect to the most serious barriers, the AAP survey findings revealed that lack of available family physicians and internists to care for older adolescents with special needs was reported as a barrier by four out of five pediatricians, including 41% who consider it a major problem. About the same proportion identified the lack of available adult specialists as an impediment to transition planning. Fragmentation of primary and specialty care in adult medicine was noted by even more pediatricians, including nearly 40% who consider this to be a major transition impediment. Lack of reimbursement for transition services was identified by slightly more than three quarters of pediatricians, with 38% reporting it as a major issue.

With respect to commonly reported barriers, nine out of ten pediatrician respondents cited that the difficulty in breaking the close relationship that has formed over the years with their adolescent patients and families impedes transition, but only about a third consider this a major barrier. Almost as many identified as a barrier the lack of information about community support resources for older adolescents and fragmentation of primary and specialty adult health care, with close to 40% considering these significant barriers. Despite the fact that the

majority of pediatricians think that transition is adversely affected by adolescents' lack of knowledge and skills, less than one fifth consider this a major impediment.

**TABLE 3. Barriers Affecting the Provision of Transition Support Services in Pediatric Practices**

Barriers	Major Barrier	Somewhat a Barrier
Lack of available family physicians and internal medicine physicians to care for older adolescents	41%	39%
Lack of available adult specialists	40	38
Lack of knowledge about or linkages to community resources that support older adolescents	39	49
Lack of insurance reimbursement for transition services	38	38
Fragmentation of primary and specialty adult health care	39	46
Lack sufficient pediatric staff time to provide transition services	36	45
Lack of pediatric staff skills in transition planning	33	46
Difficulty in breaking bond between pediatricians and adolescents and their parents	32	58
Lack of adolescent knowledge about health conditions and/or skills to self advocate during physician visits	19	65

**Conclusions**

The AAP's survey revealed major gaps in the implementation of recommended activities to facilitate an effective transition from pediatric to adult health care for adolescents with special health care needs. Few pediatric practices initiate planning for transition early in adolescence, despite guidance to the contrary. In addition, most pediatric practices do not organize their office systems or care processes to make available educational materials, a transition plan or portable medical summary, or

referrals to adult physicians. This may be due to limited staff training or technical support in transition planning and also to financial barriers. It may also be due to the lack of an identified staff member responsible for transition planning. It could also be attributed to the anxiety that pediatricians, adolescents, and their parents experience about their future health care.

Much progress needs to be made in addressing pediatric practice training, financing, adult provider availability, and consumer education issues in order to ensure that adolescents with special needs receive timely and comprehensive support as they transition out of pediatric care. With respect to pediatric practice training, several new initiatives are underway at the AAP, including the development of a clinical report on transition, which will provide a useful roadmap for transition planning in pediatric practices. This will be jointly authored by the AAFP and ACP. Additional efforts related to pediatric residency training and continuing education are under development by the AAP as well. Another strategy pediatric transition experts call for is posting a written policy that clearly defines the age limit of the practice and how the practice intends to assist its adolescent patients in gaining the knowledge and skills to effectively transfer to adult health care systems. Using electronic health record systems to incorporate prompts and reminders starting at age 14 is another strategy.

With respect to financing improvements, insurers and managed care plans need to consider alternative ways to pay for transition services as part of pediatricians' ongoing medical home functions related to care management and support, whether through visit-based fees, including telephone consults between pediatric and adult providers, or bundled care management fees. With respect to adult primary and specialist physician availability, collaborative efforts are needed between the AAP, SAM, AAFP, and ACP to implement effective ways to ensure continuity of care for this vulnerable group of young people as they move from pediatric to adult health care. With respect to consumer and parent/family education, extensive web-based information is available on the Healthy & Ready to Work National Resource Center's website, including information about Youth Advisory Councils.

More extensive outreach to pediatric practices is necessary to inform them of available community support services in order to assist adolescents with transition.

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### END NOTES

<sup>1</sup> Child and Adolescent Health Management Initiative. *2005/2006 National Survey of Children with Special Health Care Needs*. Accessed from [www.cshcnodata.org/dataquery/dataqueryprint.aspx](http://www.cshcnodata.org/dataquery/dataqueryprint.aspx) on June 1, 2008.

<sup>2</sup> U.S. Department of Health and Human Services. *Healthy People 2010* (2<sup>nd</sup> ed.). Washington, DC: US Government Printing Office, November 2000.

<sup>3</sup> Accessed from [www.healthypeople.gov](http://www.healthypeople.gov) on June 1, 2008.

<sup>4</sup> American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002; 110:1304-1306.

<sup>5</sup> Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions. *Journal of Adolescent Health*. 2003;33:309-311.

<sup>6</sup> Child and Adolescent Health Management Initiative, June 2008.

<sup>7</sup> Burke R, Spoerri M, Price A, Cardosi AM, Flanagan P. Survey of primary care pediatricians on the transition and transfer of adolescent to adult health care. *Clinical Pediatrics*. 2008;47:347-354.

<sup>8</sup> 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. *Journal of Adolescent Health*. 2008;32:225-233.

<sup>9</sup> For more information about the Healthy and Ready to Work National Resource Center, visit [www.hrtw.org](http://www.hrtw.org).

<sup>10</sup> The HSC Foundation has launched a Youth Transitions Initiative to assist young people with disabilities and chronic illness in the Washington metropolitan area and beyond to move from school to adulthood to the world of work. For more information about The HSC Foundation, visit [www.hscfoundation.org](http://www.hscfoundation.org).

The National Alliance to Advance Adolescent Health provides education, research, policy analysis, and technical assistance to achieve fundamental improvements in the way that adolescent health care is structured and delivered in the United States. Its mission is to enhance the physical and emotional well-being of adolescents, especially those who are low income and minority, by improving the health care delivery model for adolescents and achieving the infrastructure changes needed to support it. The National Alliance seeks to promote comprehensive, interdisciplinary models of physical, mental, behavioral, and reproductive health care that incorporate a youth development philosophy and operate in collaboration with schools and other community-based programs. It also seeks to ensure that all adolescents have health insurance coverage for the services they require.

For more information about our work and available publications, contact Aileen Collins at The National Alliance to Advance Adolescent Health: [acollins@TheNationalAlliance.org](mailto:acollins@TheNationalAlliance.org). Also visit our website: [www.TheNationalAlliance.org](http://www.TheNationalAlliance.org).

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