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Survey: Transition services lacking for teens with special needs

AAP Department of Research

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American Academy of Pediatrics

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RESEARCH UPDATE

Survey: Transition services lacking for teens with special needs

from the **AAP Department of Research**

Less than one-half of pediatricians routinely offer adolescent patients with special health care needs (SHCN) support services to transition to adult health care, according to an AAP Periodic Survey of Fellows.



Forty-seven percent reported assisting nearly all or most of their adolescent patients with SHCN with referrals to family or internal medicine physicians, and 45% said they assist all or most adolescents with referrals to adult specialists. About 32% offer these services to some of their SHCN adolescents.

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 SHCN. 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. One of its national objectives calls for all youth with special needs to receive services necessary to transition from pediatric to adult health care.

Until now, little has been known about how pediatricians incorporate transition support into the ongoing care of their adolescent patients with SHCN. This Periodic Survey gathered nationally representative data on transition services provided by pediatricians.

Pediatricians identified the following as major barriers to transitioning adolescents with SHCN from pediatric to adult health care:

- lack of available family/internal medicine physicians (41% reporting),
- lack of adult specialists to care for older SHCN adolescents (40%),
- the fragmentation of primary and specialty care in adult care (39%),
- lack of knowledge about or linkages to community resources that support older adolescents/young adults (39%),
- lack of insurance reimbursement for transition services (38%),
- insufficient time for staff to provide transition services (36%),
- lack of skills in transition planning (34%), and
- a hard-to-break bond between adolescents/parents/pediatricians (32%).

Only 19% said adolescents' lack of knowledge about their own condition and/or skills to self-advocate at physician visits is a major barrier.

For all of these barriers, a substantial proportion of pediatricians (38%-65%) reported them as "somewhat" a barrier to transitioning from pediatric to adult care.

Pediatricians reported helping adoles-



AAP News photo by Jeff Knox

More than 60% of pediatricians responding to an AAP Periodic Survey said transition planning from pediatric to adult health care should begin at 18-20 years of age for youths with and without special health care needs. However, few pediatricians reported that they have staff responsible for coordinating transition planning.

cents with SHCN in their transition to adult care in a variety of ways (see table).

More than six out of 10 pediatricians said transition planning from pediatric to adult health care should begin at 18-20 years of age for children with and without SHCN. Another 25% each said such planning should begin at 15-17 years of age.

Few pediatricians reported that they have staff responsible for coordinating transition planning for either group of adolescents (11% for children with SHCN and 6% for children without SHCN).

The data for this study were collected via Periodic Survey #71 conducted from January to May 2008. Surveys were mailed to a random sample of 1,605 nonretired U.S. post-trainee AAP members, with a response rate of 64%. Analysis was limited to 628 respondents who provide health supervision for patients 12 years of age and older.

The survey was conducted in collaboration with the AAP Committee on Adolescence and the National Alliance to Advance Adolescent Health, with funding from the HSC Foundation, Washington, D.C.

RESOURCES

For details on findings from Periodic Survey #71, visit www.aap.org/research/periodicsurvey/PS71transition_%20care_%20factsheet.pdf.

For more information on the Periodic Survey, contact Karen O'Connor at 800-433-9016, ext. 7630, or koconnor@aap.org, or visit www.aap.org/research/periodicsurvey/ps0f.htm.

Transition support services offered to adolescents with special health care needs

(% of pediatricians reporting)

Transition services	For nearly all or most	For some
Assist with referral to specific family or internal medicine physicians	47	33
Assist with establishing referral to specific adult specialists	45	32
Discuss consent and confidentiality issues prior to age 18	33	27
Assist with medical documentation for program eligibility (e.g., Supplemental Security Income, vocational rehabilitation, college)	32	34
Discuss assent to care issues prior to age 18	31	27
Assist in creating a portable medical summary	27	26
Support family or internal medicine physicians with education and consultation	23	30
Assist with identifying options to maintain health care insurance after age 18	19	22
Create an individualized health care transition plan	12	26
Provide adolescents/parents with an educational packet or handouts	11	14

Source: AAP Periodic Survey of Fellows #71, 2008

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