Survey: Transition services lacking for teens with special needs
AAP Department of Research
AAP News 2009;30;12
DOI: 10.1542/aapnews.20093011-12

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http://aapnews.aappublications.org/cgi/content/full/30/11/12
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-

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.

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/psof.htm.

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## Transition support services offered to adolescents with special health care needs

<table>
<thead>
<tr>
<th>Transition services</th>
<th>For nearly all or most</th>
<th>For some</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assist with referral to specific family or internal medicine physicians</td>
<td>47</td>
<td>33</td>
</tr>
<tr>
<td>Assist with establishing referral to specific adult specialists</td>
<td>45</td>
<td>32</td>
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<tr>
<td>Discuss consent and confidentiality issues prior to age 18</td>
<td>33</td>
<td>27</td>
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<tr>
<td>Assist with medical documentation for program eligibility (e.g., Supplemental Security Income, vocational rehabilitation, college)</td>
<td>32</td>
<td>34</td>
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<tr>
<td>Discuss assent to care issues prior to age 18</td>
<td>31</td>
<td>27</td>
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<tr>
<td>Assist in creating a portable medical summary</td>
<td>27</td>
<td>26</td>
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<tr>
<td>Support family or internal medicine physicians with education and consultation</td>
<td>23</td>
<td>30</td>
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<tr>
<td>Assist with identifying options to maintain health care insurance after age 18</td>
<td>19</td>
<td>22</td>
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<tr>
<td>Create an individualized health care transition plan</td>
<td>12</td>
<td>26</td>
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<tr>
<td>Provide adolescents/parents with an educational packet or handouts</td>
<td>11</td>
<td>14</td>
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*Source: AAP Periodic Survey of Fellows #71, 2008*
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