

# Survey of Primary Care Pediatricians on the Transition and Transfer of Adolescents to Adult Health Care

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The transition and transfer from pediatrics to adult health care of youth with and without special health care needs has become a focus of professional organizations, health care insurers, national policy makers, and providers. To understand transition and transfer at a primary care practice level, all primary care pediatricians in Rhode Island were surveyed. Responses were received from 103 of 169 (60.9%) practicing pediatricians. Few responders had practice policies on transfer. Most reported that transition should begin later than recommended. Few practices communicated with

adult providers at transfer. Most reported that health insurers were of little help in transfer. Many pediatric practices had young adults after age 22 and many with special needs. Responders reported adolescents left their practices by 1 of 6 methods. The survey indicates the need for further study of transition and transfer and the need for additional training and education if transfers are to be successful.

**Keywords:** adolescents; transition; children and youth with special health care needs (CYSHCN)

**T**he issue of the transition of adolescents and young adults with special health care needs from pediatric to adult health care was compellingly put forward in the 1989 Surgeon General's report *Growing Up and Getting Medical Care: Youth with Special Health Care Needs*.<sup>1</sup> In subsequent years, numerous articles have been published on the need for and challenges to transition and transfer of young adults to the adult health care system.

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Most of the earlier articles on transition relate to the transfer of adolescents with special needs from pediatric subspecialty care to adult specialists within the tertiary care setting. In 2001, the American Academy of Pediatrics partnered with the American Academy of Family Physicians, the American College of Physicians, the Society of Internal Medicine, and other professional organizations to develop a consensus statement on the transition of adolescents with special needs to adult health care.<sup>2</sup> The consensus statement and its accompanying articles addressed several issues concerning the transition and transfer of adolescents with special needs from the primary care pediatric setting to adult care.

Inherent in the consensus statement and the accompanying articles is the recognition that transition is a planned and orderly process of change from child oriented to adult models of care. Transfer, on the other hand, refers to the termination of care by a children's health care provider and reestablishing care with an adult care provider.<sup>3</sup> With some pediatric care providers, particularly family physicians

and Med/Peds-trained providers, transition of care to adult models takes place although transfer of care may not be anticipated. The questions of transition and transfer of youth with special health care needs and the role of the “medical home” were addressed in 2 of the accompanying articles.<sup>4,5</sup> The publication of the consensus statement in 2002 intensified interest in the subject of health care transition, as did the transfer timeline proposed in Healthy People 2010.<sup>6</sup> It also renewed the discussion in the role of the primary care pediatrician in the transition and transfer of youth with special needs to adult care.

Several recent articles have discussed the transition of care from the perspectives of the youth, the family, and providers. These reports provide important, useful, and essential insights into the needs, feelings, and anxieties faced by the young adult patients and their families.<sup>7,8</sup> The barriers that challenge youth, families, and providers are also highlighted in these reports.<sup>9</sup> The State and Local Area Integrated Telephone Survey, (SLAIT Survey), in focusing on the medical home, indicates that only 6% of families report meeting the goal that “All youth with special health care needs (YSHCN) will receive the services necessary to make transition to all aspects of adult life.”<sup>10</sup> At present, the transition and transfer of youth with and without special needs remains problematic, or as characterized by McDonough and Viner<sup>11</sup> as “Lost in Transition”<sup>11</sup> and by Reiss,<sup>12</sup> “Health Care Transition: Destinations Unknown.”

Despite the renewed attention, barriers remain for the transition of young adults with special health care needs to adult health care services. Findings from the 2002 National Survey of Children With Special Health Care Needs indicate that most young adults do not receive adequate transition services. Fifty percent of the parents reported that their doctor discussed how the health needs of their adolescent might change in adulthood. However, only 30% of providers had developed a plan to address these changing health needs, and only 30% had discussed seeing a doctor who specializes in adult medicine.<sup>7</sup>

Blum<sup>13</sup> outlined 4 transition outcomes for young adults:

1. continue to receive care from pediatric providers,
2. receive care from both pediatric and adult providers,
3. receive all care from adult providers, or

4. young adults have no connection with the health care system after leaving the pediatric system of care.<sup>13</sup>

The barriers to a successful transition to adult systems of care have been documented and discussed. These included the long-term patient–physician relationship, differences between the pediatric and adult models of care, limited adult provider training on adolescent- and child-onset disorders, patients’ level of maturity and understanding, family stressors, distorted perceptions of the adult health care system, difficulty identifying primary care providers for adults, family and adolescent resistance to transfer, and lack of institutional support.<sup>4,5,7</sup>

Several models promote the health care transition process for young adults, most of which have focused on the transition of adolescents with a specific condition or the transition from a pediatric subspecialty to adult subspecialty providers. There has been less focus on the transition process within the primary care setting.<sup>14</sup> The intent of this survey was to determine the present state of the health care transition process for adolescents and young adults with and without special health care needs from the perspective of the primary care pediatrician. The survey reported here was intended to look at the present state of the transition and transfer from the primary care pediatricians’ perspective so that the pathway for successful health care transition could be better navigated.

## Methods

### Survey Instrument Design

A 13-question survey instrument was developed from feedback from discussions with practicing primary care pediatricians and parent and patient focus groups about the transition and transfer of adolescents to adult health care. The survey questions are listed in Table 1. The survey questions were not validated nor was their reliability established before the survey was mailed.

The survey was intended as an initial study to gain preliminary descriptive information about the existing state of transfer from a primary care pediatric perspective and the understanding of the processes by which adolescents leave primary care pediatric practices. The survey was also intended to

**Table 1.** Survey Questions on Transition to Adult Care

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1. Does your office have a written policy on the transition and transfer of adolescents to adult health care? (Yes) (No)
2. At what age do you feel the transition process should begin? ( ) Early adolescence, ( ) 1-year prior to transfer, ( ) At time of transfer, ( ) Other
3. At what age do you usually recommend the transfer of adolescents to adult health care? \_\_\_\_Age in years
4. What percentage of adolescents in your practice are above the age you usually recommend transfer to adult care? \_\_\_\_%
5. Of the adolescents over the usual age of transfer what percentage has special Needs? \_\_\_\_%
6. What is the age of the oldest patient in your practice? Age in years \_\_\_\_? Does the patient have special needs? (Yes) (No)
7. Do you have difficulty finding adult providers for transferring adolescent patients? (Yes) (No) If yes, how difficult? ( ) Mild ( ) Moderate ( ) Very
8. Do you have difficulty finding adult providers for adolescents with special Needs? (Yes) (No) If yes, how difficult? ( ) Mild ( ) Moderate ( ) Very
9. Do you send a written summary to adult provider when adolescent transfer? (Yes) (No)
10. Do you send a written summary for adolescents with special needs? (Yes) (No)
11. Do you typically communicate directly with adult providers to assure that transfer was successful? (Yes) (No)
12. Do health insurance plans help with the transfer of adolescents to adult health care providers? (Yes) (No)
13. Estimate the percentage of adolescents with and without special needs leaving your practice by each method of transfer.

Age out        \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN  
Drop out        \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN  
Forced out      \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN  
Hang out        \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN  
Move out        \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN  
Transfer out     \_\_\_\_% with SHCN, \_\_\_\_% Without SHCN

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Note: SHCN = special health care needs.

look at some potential barriers to transfer and the differences experienced by providers in the transfer of adolescents with and without special health care needs. The survey addressed issues in the following domains: the policies and practices, timing of transition and transfer, the processes of adolescent transfer, barriers to transfer, the role of health plans, and the practitioners' experiences with transfer of adolescents with and without special needs.

Demographic information was requested from the primary care pediatricians along with information about their practices and practice setting. The final question asked pediatricians to estimate, using the best means available to the practice, the percentages of adolescents with and without special health care needs leaving their care by each of the 6 methods of transfer listed and defined in Table 2.

These 6 methods of transfer were compiled from earlier discussions with primary pediatricians. The method of transfer reported by pediatricians involved in the presurvey discussions included being *aged out*, when an adolescent leaves the practice upon reaching an age determined by the practice. Many adolescents were reported to *drop out* of a practice by simply no longer coming for care and were lost to follow-up. Some adolescents were *forced out* of practices by loss

**Table 2.** Description of Methods of Adolescent Transfer From Pediatric Practice

Method	Explanation
Age out	Leaves practice upon reaching an age determined by the practice
Drop out	Stops coming for care and is lost to follow-up
Forced out	Leaves for reasons not controlled by patient or practice
Hang out	Continues with practice after age limit of practice
Move out	Leaves practice to seek care from other provider
Transfer out	Coordinated transfer to adult health care provider

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of or changes in health care coverage or by other factors not directly controlled by the patient or the practice. Other young adults *hang out* in a practice, continuing to receive care after the age limit usually set by the practice for transfer or termination of adolescent care. Many teenagers and young adults simply *move out* and leave the practice to seek care from other provider. Few providers reported an active and coordinated program of *transfer out* to a health care provider for adult patients.

## Eligibility Criteria

Eligible survey participants were those physicians who were licensed and actively practicing primary care pediatrics in the state of Rhode Island during 2004. A review of the licensing records of the Rhode Island Department of Health indicated that 388 pediatricians were licensed by the state. Of these, 169 were identified to be actively practicing primary care within the state through review of health department, hospital, and other public records. Excluded were licensed pediatricians in subspecialty practice, in nonclinical or administrative positions, retired pediatricians, and those practicing outside of the state.

## Survey Administration

All 169 primary care pediatricians practicing in the 71 identified practices were mailed an initial survey questionnaire. If there was no response, second and third surveys were mailed at 4-week intervals, and each physician was called and encouraged to participate in the survey. Surveys were coded to protect the identity of each participant. Face-to-face or phone interviews after the survey with selected practicing pediatricians were conducted to clarify some of the issues that were brought forward by responses to specific survey questions.

## Data Analysis

Data were entered into an Excel database (Microsoft, Redmond, Washington) and imported into SAS (SAS Institute, Cary, North Carolina) for statistical analysis. The format of the survey questions and the methods of data collections limited analysis to use of 95% confidence intervals (CIs) to test statistical differences between groups. The  $\chi^2$  test was used where applicable, such as with the demographic and practice data provided by responders.

## Results

Responses were received from 103 of the 169 surveyed pediatricians for a response rate of 60.9%. Table 3 summarizes the demographic characteristics of the respondents. No demographic or practice data were available for nonresponders; therefore, no comparative analysis could be made between responder and nonresponder groups.

**Table 3.** Demographic and Practice Characteristics of Survey Responders

Responder Characteristics	Frequency, No.	% (SD)
Responders/surveyed pediatricians	103/169	60.9
Age, mean y	47.4	(10.7)
Sex		
Female	48	48.5
Male	51	51.5
Years in practice		
1-5	14	14.2
6-10	24	24.7
11-15	9	9.3
16-20	18	18.6
>20	32	33
Practice setting		
Private office	74	76.3
Community health center	7	7.2
Academic center	14	14.4
Other	2	2.1
Physicians in practice, No.		
1	11	11.3
2-3	35	36.1
4-5	27	27.8
>5	24	24.7

Note: SD = standard deviation.

## Current Health Care Transition Practice

The responding primary care pediatricians reported that only 13 practices (13%) had written policies on the transition and transfer of adolescents to adult care, 99 responders (96%) reported that the transition process should begin either 1 year prior or at the time of transfer, and only 3 (3%) indicated that transition should begin in early adolescence according to the recommendations in the consensus statement. The recommended ages for transfer of adolescents from pediatric to adult health care ranged from 15 to 22 years, with 43.6% of responders recommending transfer at 18 years and 27.7% recommending transfer at 21 years. The age of transfer notwithstanding, 36.1% of responders reported having patients older than age 22, for whom they continued to provide care, and 22.7% had patients older than age 25. Patients aged between 25 and 30 were still seen by 15.5% of providers, and 7.2% had patients older than age 30. All patients aged 25 or older still being cared for in the primary care pediatric settings were those with some special health care need.

## Pediatric and Adult Provider Communication

An unanticipated result of the survey was that 70% of responders reported having no difficulty in finding adult providers for adolescents. Of the 30 pediatricians (30.0%) who reported having difficulty finding adult providers, 18.2% reported mild difficulty, 72.7% moderate, and 9.1% severe difficulty. For adolescents with special needs, 50.5% of responders reported having difficulty in finding adult care and 49.5% did not. Of those reporting difficulty, it was mild in 19.2%, moderate in 40%, and very difficult in 40%.

The report of not having difficulty was unanticipated and prompted postsurvey interviews and discussions about the transfer process in several types of practices. These discussions revealed that there were several reasons why difficulty was not experienced. In some multispecialty practices that included adult providers on staff, young adults with and without special needs were directly transferred to adult care within the practice. This was, however, the case with only a few community health centers and multispecialty practices. Pediatricians who did not experience difficulty with transfer reported not being actively involved in the process. Some providers simply advised the parents that the practice would not be able to provide care to an adolescent after a specific age. Other pediatricians planned to continue care either because of an ongoing relationship with the child and family or because the provider foresaw difficulties in the transfer process, especially for young adults with special health care needs.

Most responders (87%) indicated that their practices had not yet developed written practice policies on the transition and transfer of adolescents with and without special needs. Questions were posed about the transfer process relating to communication before and after the transfer. Of responding pediatricians, 70% reported they did not provide transfer summaries for adolescents in general, whereas 50% did provide written summaries for those with special health care needs. Only 18% of responders reported that they communicate with adult providers after transfer of a pediatric patient, whereas 82% did not. According to 97% of responders, health care plans and insurers did not help in the transition and transfer process.

## Method of Transition

The last question of the survey focused on how adolescents were transferred from pediatric practices to adult health care. From presurvey discussions with primary care pediatricians, it became clear that young adults transferred from pediatric practices by several different methods. These methods of transfer were given descriptive names and included *age out*, *drop out*, *forced out*, *hang out*, *move out*, and *transfer out*, and are described in Table 2. Primary care pediatricians were asked to estimate the percentage of adolescents both with and without special needs transferring by each of the 6 transfer methods.

The responses from primary care pediatricians about the method of transfer for those with and without special health care needs are summarized in Table 4 and Figure 1. Age out is the most common method for both adolescents in general and those with special needs to leave pediatric care, with estimates of 29.5% and 26.7%, respectively. Drop out occurs more frequently for adolescents without special needs (19%) than for those with special needs (7%). Similarly, more adolescents without special needs were forced out of pediatric practice (11.4%) than those with special needs (8%) and more moved out (22%) than those with special needs (13.4%). Conversely, but not surprising to primary care pediatricians, many more adolescents with special health care needs remained in pediatric care, or hung out (28.4%), compared with their peers without special needs (6.6%).

As shown in the 95% CIs, there were no statistical differences between patients with and without special needs in aging out, being forced out, or transferring out of a primary care practice. However, statistical differences were identified by 95% CIs between these 2 groups, with no overlap of 95% CI between groups with and without special health care needs for dropping out of a practice, moving out, and hanging out after the usual age of transfer for the individual practices.

Analysis by  $\chi^2$  found no statistically significant differences in responses to questions related to office policy or practices, age of transfer, difficulty in transfer, or method of transfer based on responder or practice characteristics. Age, sex, and practice setting did not appear to be related to the practices or experiences of the responding primary care pediatricians.

**Table 4.** Reported Method of Transfer for Adolescents With/Without Special Needs

Method	Special Health Care Needs <sup>a</sup>	
	Without, mean % (95% CI)	With, mean % (95% CI)
Age out	31.83 (25.50-38.16)	26.87 (18.34-35.39)
Drop out <sup>b</sup>	20.65 (16.38-24.92)	7.13 (3.48-10.78)
Forced out	12.33 (9.08-15.87)	8.00 (3.11-12.89)
Hang out <sup>b</sup>	7.10 (5.18-9.02)	28.60 (20.33-36.87)
Move out <sup>b</sup>	23.81 (19.27-28.35)	13.50 (7.78-19.22)
Transfer out	12.35 (7.40-17.28)	16.72 (9.85-23.87)

Note: CI = confidence interval.

a. Statistically significant for mean (95% CI) at  $P < .05$ .

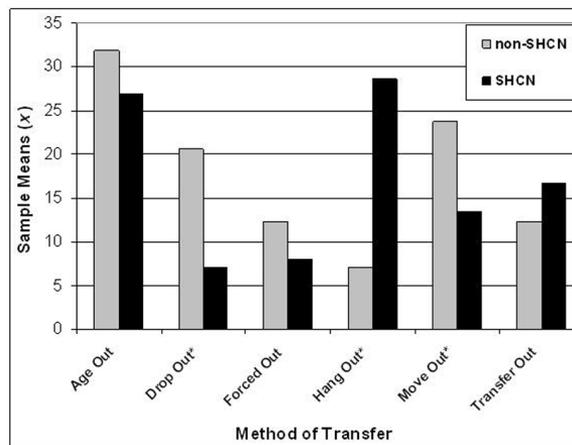
b. Statistically significant at  $\alpha$  level = 0.05.

## Discussion

The survey of all identified primary care pediatricians practicing in a single state was undertaken as an initial study to examine the process of health care transition and transfer of adolescents from pediatric to adult health care. One objective was to understand the existing state of transfer from the primary care pediatric perspective and to understand the processes by which adolescents leave primary care pediatric practices. The survey was also intended to help to understand some potential barriers to transfer and the differences in transfer for adolescents with and without special health care needs. The survey sent to primary care pediatricians in the state asked for a mix of factual responses, opinions, and estimations because hard numeric data were not available from most practices.

Nevertheless, and with these limitations in mind, the survey gives some insight into the state of the transition and transfer of adolescent and young adults from pediatric to adult health care. Few providers (13%) reported that their practices had an established written policy on transition and transfer of youth to adult care. Of the responding pediatricians, 97% believed that the transition should occur at a later age than the recommendation in the consensus statement on the transition of young adults with special needs that the transition process should begin in early adolescence.

Despite the interval of more than 20 years from the Surgeon General's report on the health care of children and adolescents with disabilities, more than 10 years from the introduction of the concept



**Figure 1.** Reported method of transition for adolescents with and without special health care needs (SHCN).

of the medical home, and 5 since the launching of the 2010 Express, the plan for the transition and transfer of adolescents to adult care has yet to become a practical and functional aspect of care for many pediatric care providers. Most respondents reported that they did not usually communicate with a provider of adult care before or after transfer. Indeed, many providers were not actively involved in the transition of young adult patients to providers of adult health care. It would appear from this survey that practicing pediatricians are not yet fully on board with the consensus statement on health care transitions. Existing barriers to transition need to be addressed, and adolescents with special health care needs are a group of particular concern. However, the findings from the present survey are consistent with those of the health statistics in the SLAIT Survey report that 6% of children and youth with special health care needs meeting the goal of "All youth with special health care needs (YSHCN) will receive the services necessary to make transitions to all aspects of adult life."<sup>10</sup>

Geenen et al<sup>15</sup> proposed 13 specific transition activities for primary care providers. Many of these recommendations have not yet become an integral part of primary care pediatric practice. Additional training and education on the need for transition and on the processes and procedures of transfer is needed if the goals of Healthy People 2010 are to be met.<sup>16,17</sup> The Society of Adolescent Medicine has made a number of similar recommendations relating

to the timing and process of transition and outlines the need for education and training for health care providers for both pediatric and adult patients.<sup>18</sup> In addition, although the roles of health care plans and insurers are seen as problematic by the responders to this survey, health care plans could be useful partners and provide valuable links between pediatric and adult care providers in the transfer process.<sup>19,20</sup>

The survey reported here shares many of the shortcomings and limitations addressed by Betz<sup>14</sup> and Cull et al,<sup>21</sup> which are inherent in the survey format. In addition, the survey form sent to primary care pediatricians asked for a mix of factual responses, opinion, and estimations because quantitative data were not available from most practices. This limited statistical analysis. Nevertheless, and with these limitations in mind, the survey gives some important insights into the present state of the transition and transfer of youth to adult health care. It also points to the need for more objective and quantifiable assessment of the transfer process from both the pediatric and adult health care perspectives. Although this initial survey of primary care pediatricians in a single state may not be generalizable to other states or settings, the responses to this survey do parallel previous reports of transition and transfer of young adults with special needs to adult health care.

Descriptive studies, such as the survey reported here, are useful in providing a basis for understanding the challenges faced in moving from a consensus statement to a process that is both workable in the practice setting and beneficial for patients and families. As pointed out by Cull et al,<sup>21</sup> survey strategies that can better address response bias are needed that can provide more generalizable conclusions. Studies that have a theoretic basis and are able to generate testable hypotheses will have to wait for a consensus to develop on models of care and transition, goals of transition and transfer, agreement on basic terminology, the development of valid and reliable research questions, and controlled and analyzable study designs. Specific areas of research and study design that have health service implications, that demonstrate efficacy, and provide evidence-based clinical outcomes have been recommended by others.<sup>14</sup>

Freed and Hudson<sup>22</sup> have reviewed the current state of knowledge and practice of transition and have recommended future directions in transition to adult care. The recent release of the statement of Joint Principles of the Patient-Centered Medical

Home demonstrated the commitment of both child and adult health care providers to move forward with concepts of comprehensive, coordinated, patient- and family-centered care, of which transition and transfer are significant elements.<sup>23</sup>

The present study focused on the state transition and transfer of young adults from the pediatric practice perspective. Additional studies that look at transfer from the adult providers' point of view need to be undertaken. Moving beyond research, plans, procedures, and programs that facilitate efficient transfer of care must be developed. Further study and program development are clearly warranted and needed if the goal of the Healthy People 2010 for the transfer of adolescents with and without special need is to be achieved.

Transition and transfer of adolescents to adult health care are complex and challenging, with many issues yet to be fully addressed. The processes of transition and transfer in both pediatric and adult care spheres need to be further studied. Further study should be done to develop the evidence-basis training and interventions that are needed to facilitate successful transition and transfer to adult health care.<sup>24</sup> Health care transition in a previously cited article by Reiss and Gibson<sup>12</sup> has been labeled as "destinations unknown." Although we are not yet at our final destination in the process of transition of youth with special health care needs to adult care, the road to be traveled is becoming clearer and more easily and successfully traveled.

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