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# Improving Transition From Pediatric to Adult Cystic Fibrosis Care: Lessons From a National Survey of Current Practices

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## What's Known on This Subject

Improved survival of children with chronic health conditions has led to an increasing need to transition their health care to adult-oriented systems. Qualitative studies, surveys and commentaries have shown widespread patient and provider dissatisfaction with the transition process.

## What This Study Adds

CF providers have been early and active contributors to advocacy and research on health care transition. This study is a comprehensive assessment of transition practices at CF centers nationwide. Findings may extrapolate to a wide variety of chronic conditions.

## ABSTRACT

**OBJECTIVES.** More than 500 000 adolescents with special health care needs age into adulthood each year in the United States, and there is growing recognition of the need for support of their transition to adult-oriented health care. Because of improved survival, cystic fibrosis has experienced this increasing transition need, and cystic fibrosis policy leaders responded by mandating the transition of adults with cystic fibrosis to adult-focused cystic fibrosis care programs by 2000. The primary objective of this study was to characterize in detail recent transition practices at US cystic fibrosis programs, to identify areas for improvement and to serve as a model for other diseases. A secondary objective of this study was to develop and validate a survey for formal assessment of transition practices.

**METHODS.** A 105-question survey on key aspects of transition was administered to cystic fibrosis care team members from all 195 US Cystic Fibrosis Care programs. Rates of adherence to recommended components of transition care were measured.

**RESULTS.** A total of 448 surveys were obtained from 170 (87%) of 195 cystic fibrosis programs. Although transfer of care occurs at a median age of 19 years, initial discussion of transition does not occur until a median age of 17 years, limiting time to foster self-care skills. Only half of programs consistently perform a transition readiness assessment, 28% of centers offer visits focused on transition, and <10% have a written list of desirable self-management skills.

**CONCLUSIONS.** There is significant variability in transition support provided to young adults with cystic fibrosis, but there are simple steps that may lead to more consistent delivery of transition services. Methods of assessment and lessons learned from transitioning young adults at US cystic fibrosis programs may serve to improve transition for individuals with other childhood diseases.

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### Key Words

health care transition, cystic fibrosis, adolescents with special health care needs

### Abbreviations

CF—cystic fibrosis  
CFF—Cystic Fibrosis Foundation  
PCP—primary care provider

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**M**ORE THAN 500 000 adolescents with special health care needs age into adulthood each year in the United States.<sup>1</sup> Among these are individuals with a wide diversity of chronic illnesses, including, among many, congenital heart disease, neuromuscular disease, sickle cell disease, juvenile diabetes, and cystic fibrosis. Both a 2001 consensus statement by the American Academy of Pediatrics, Academy of Family Physicians, and American College of Physicians/American Society of Internal Medicine<sup>2</sup> and the *Healthy People 2010* guidelines emphasize the need for greater support of transition of youth with special health care needs from pediatric to adult-oriented health care. Numerous other publications have highlighted the challenges faced when youth with special health care needs seek transition to adult-oriented care.<sup>3-9</sup>

Cystic fibrosis (CF) is a striking example of a disease with increasing need for programs that support transition from pediatric to adult-oriented health care. There has been a dramatic improvement in survival in CF, a disease

How often are the following items assessed in your clinic?

Whether a patient is able to independently...	Always	Usually	Sometimes	Rarely	Never
List their medications & their function	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perform airway clearance without reminders/supervision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact their providers without relying on family members/other supports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Plan for and attend clinic visits without family assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify conditions requiring emergency care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify their source of insurance coverage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact their insurer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identify their entitlements/ benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the patient has the developmental maturity to function well in an adult-oriented care system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

FIGURE 1  
Survey items for readiness assessment.

traditionally considered a disease of childhood: median predicted survival age in the United States has increased from only 14 years in 1969 to >36 years in 2005.<sup>10</sup> To support the health and well-being of this new generation of adults with CF, the Cystic Fibrosis Foundation (CFF) mandated in 1996 that approved CF programs must provide adult CF care consistent with 1 of 4 adult-care models by the year 2000 and set an expectation that ≥90% of patients past their 21st birthday would be transitioned to these programs.

CF providers have been early and active contributors to advocacy and research in health care transition.<sup>11–13</sup> More than 85% of individuals with CF in the United States are followed at CFF-accredited centers,<sup>14</sup> indicating that CFF center-based health care transition data represent a comprehensive national perspective on transition within a disease-specific community. Studying the experience of developing adult-oriented care for individuals with CF serves as a particularly effective method for identifying both valuable and problematic strategies in adult health care transition for all children with special health care needs. This study therefore sought to characterize in detail the transition experiences and practices of current US CF programs using a structured survey of the multidisciplinary teams at CF programs nationwide.

## METHODS

### Survey Development

We identified elements of health care transition processes through a literature review. A Medline search on “health care transition” and “transition of care” yielded 5137 publications. Titles were reviewed to identify articles that were relevant to the health care transition of adolescents and young adults. A Google search on health care transition identified Web sites that provide information and resources on health care transition. Literature and Web content were reviewed to guide the content elements of the survey.

Health care transition has been defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”<sup>15</sup> To assess systematically transition activities at CF programs, we constructed a conceptual model of the

process of health care transition, identifying discrete activities that facilitate transition. Transition activities that might be offered at CF programs were grouped into 7 functional domains: patient preparation, patient readiness assessment, coordination of services and benefits, information transfer (communication and medical summary), primary and preventive health care, patient follow-up and program evaluation, and transition program self-evaluation. Closed-ended and open-ended questions were used to assess the presence of specific processes, the consistency with which they occurred, and the method by which they were supported. Figure 1 offers an example of the series of survey questions regarding readiness assessment. A 10-point rating scale was used for clinical center self-evaluation of performance in each domain and overall transition effort.

Clinicians and researchers with expertise in CF care and transition and national experts in health care transition reviewed the original survey tool. Their input on the domains and the range of included items were used for construct validation. A final, abbreviated version was completed and administered sequentially to a convenience sample of multidisciplinary professionals who provide pediatric and adult CF care to assess ease of administration and to verify clarity of content. The final survey and administration plan were approved by the Johns Hopkins University School of Medicine institutional review board and by the US CFF.

The final survey included 3 closed-ended items related to respondent demographics, 96 closed-ended items grouped within domains of transition services, 3 closed-ended questions for subjective report regarding the CFF transition mandate and the financial impact of transition on centers, and 3 open-ended questions for additional concerns; a total of 105 questions. The full survey is available for review as an online supplement, which is published as supporting information on [www.pediatrics.org/content/full/121/5/e1160](http://www.pediatrics.org/content/full/121/5/e1160).

### Survey Administration

All 195 US-based CF programs were contacted by e-mail or telephone, using information from the CFF Web site ([www.cff.org](http://www.cff.org)), to identify appropriate staff and to confirm mailing information. Responses were solicited from

all center directors and nurse coordinators, and additional personnel who were identified as highly involved in the care of patients with CF (eg, adult or pediatric care directors, nurses, nutritionists, respiratory therapists, clinicians without formal administrative roles, social workers). Nonresponders were contacted by e-mail or telephone to encourage survey completion, and a second survey copy was mailed within 4 weeks of initial contact. Data collection was completed between January and June 2004.

### Survey Analysis

Survey results were entered into Microsoft Access 9.0 (Microsoft Corp, Redmond, WA) by using a template to limit entry errors. A random selection of 5% of surveys were reentered to assess accuracy of data entry. Data were transferred to Intercooled Stata 8.0 (Stata Corp, College Station, TX) by using StatTransfer 7.0 (Circle Systems, Inc, Seattle, WA). A subset of respondents completed a second, identical survey after a 1- to 3-week interval to evaluate internal consistency of the tool. Correlations coefficients and  $\kappa$  statistics were used to assess intracenter and intercenter variability. Descriptive statistics for transition processes were generated using frequency weighting to account for variable numbers of respondents across centers. Analysis of variance tests were used to compare responses across respondent roles and program types.

### RESULTS

Responses ( $n = 448$ ) were received from 87% (170 of 195) of CFF-accredited programs. The number of respondents per program ranged from 1 to 11, with a median of 2. Fifty-two centers were represented by a single respondent. Despite the survey length, almost all surveys were fully completed and often included lengthy responses to open-ended questions at the end of the survey. The response rate for the final closed-ended question was 92%. Redundant data entry on a random sample of surveys identified a data entry error rate of <1%.

#### Survey Characteristics

Repeat surveys were completed by individuals at 6 (3.5%) of 175 centers to assess intrarater reliability, with overall  $\kappa$  values ranging from 0.81 to 0.99. Interrater reliability within programs was assessed for a subset of centers selected to include a range of total number of respondents within the program.  $\kappa$  values for transition summary scores varied across domain. For example, patient preparation and readiness assessment values ranged from 0.78 to 1.00 and 0.89 to 0.95, respectively; however, coordination (0.58–1.00), communication (0.42–0.97), and follow-up (0.39–0.94) values were lower. Internal consistency of the domains was supported by values of Cronbach's coefficient  $\alpha$ , which ranged from 0.82 to 0.86.

#### Respondent Characteristics

The majority (58%) of respondents were center directors and nurse coordinators (Table 1). More than 70% of

**TABLE 1 Demographics of Survey Respondents**

Role of Respondent	<i>n</i>	%
Physician	192	43
CF center director	98	22
Program director (adult or pediatric)	62	14
Other (physician)	32	7
Nurse coordinator	160	36
Social worker	38	8
Respiratory therapist	14	3
Dietitian	19	4
Other (nonphysician)	22	5
Total	445	

respondents reported their tenure at the program as  $\geq 5$  years. Physician respondents were approximately evenly distributed among those with clinical responsibilities that were exclusively pediatric or exclusively adult and those that combined pediatric and adult care (Table 2). Transition domain scores did not differ significantly by the team role of the respondent with 1 notable exception: adult care directors gave significantly worse scores to the quality and consistency of transition preparation than did their pediatric counterparts (3.4 vs 2.7 on a 5-point scale with the best score being 1.0;  $P = .02$ ). Results for a subset of programs for which responses were obtained from both of 2 readily identified roles, program director and nurse coordinator, were analyzed and compared with the results drawn from broader or more variable respondents and did not differ significantly.

Key findings in each of the 7 transition domains are highlighted. Full results are available in the online supplement, which is published as supporting information on [www.pediatrics.org/content/full/121/5/FirstPageNo](http://www.pediatrics.org/content/full/121/5/FirstPageNo).

#### Patient Preparation

Initial discussion of transition occurred at a median age of 17 years, ranging from "at the time of diagnosis" to 25 years of age. Transfer of care occurred at a median age of 19 years, with a range of 14 to 30 years. Half of programs allow patients to delay or decline transition. The most frequently cited reasons for delaying or deferring transition were end-stage disease, developmental delay, patient or physician unwillingness, or patient awaiting lung transplantation. Only 28% of programs consistently offer visits or clinics focused on transition. Fewer than 25% of programs "usually" or "always" provide educational materials about transition to patients and families, and fewer than half provide a transition timeline or designate a specific team member to be responsible for key elements of transition (Table 3).

**TABLE 2 Physician Respondents' Self-Report of Areas of Primary Responsibility**

Areas of Responsibility	<i>n</i>	%
Pediatric only	60	31
Adult only	72	38
Both pediatric and adult	60	31

**TABLE 3 Patient Preparation Domain Results**

Parameter	Always/Usually, %	Sometimes, %	Rarely/Never, %	Don't Know, %	N
How often does your center's pediatric providers or staff					
Involve the family in transition planning?	62	17	13	8	419
Discuss the process of transition?	61	25	14	0	419
Provide a transition timeline to patient?	49	18	25	8	418
Ask about patient's health goals?	48	27	10	14	417
Assess patient's understanding of the transition process?	47	23	20	10	419
Designate who is responsible for key elements of transition?	44	14	29	13	418
Schedule a visit focused on transition?	28	20	44	8	418
Provide educational materials about transition to patients?	24	24	41	11	419
Does your center have a written protocol for the process of transition?	Yes = 18%	No = 82%			411

**Readiness Assessment**

Only half of CF programs consistently perform readiness assessments, and <10% have a written list of desirable self-management skills. Among programs that do perform readiness assessments, patients' ability to list their medications and describe their function was assessed most frequently (85%), along with patients' ability to perform airway clearance without reminders or supervision (83%) and ability to function well in an adult-oriented health care system (76%); however, even in these programs, readiness assessments were infrequently reported for skills such as whether patients were able to identify and contact their insurer (26%) or understand their insurance benefits (43%). Even when deficiencies in readiness were identified, only 18% of programs had specific programs designed to foster the development of readiness skills (Table 4).

**Primary and Preventive Health Care**

Sixty-two percent of programs reported that their clinic patients "usually" or "always" had a primary care provider (PCP) other than the CF care team. The CF teams were "usually" or "always" aware of the PCP and in-

formed them about a transfer of CF care at 68% of programs. Notably, >10% of programs reported that their patients "never" or "rarely" had another PCP. Regarding whether age-appropriate health issues were discussed in CF clinic, 38% of programs reported that they did not do so consistently. Among programs that reported age-appropriate behavioral risk counseling, occurrence varied by topic, with high scores for dieting behavior (89%), educational/vocational plans (85%), substance abuse/smoking (83%), and depression/anxiety (81%) and lower scores for fertility/pregnancy intention (72%) and sexual activity (65%).

**Coordination of Services and Benefits**

Anticipated changes in insurance coverage were "usually" or "always" discussed at 76% of programs. More than 80% of programs formally assign this responsibility to a specific team member; however, only one third provide written information on retaining benefits.

**Information Transfer (Communication and Medical Summary)**

More than 80% of programs reported discussing transition of individual patients at pediatric team meetings;

**TABLE 4 Patient Readiness Assessment Domain Results**

Parameter	Always/Usually, %	Sometimes, %	Rarely/Never, %	Don't Know, %	N
How often is an assessment of a patient's readiness for transition performed by center providers or staff?	52	19	29	0	394
If your center performs assessments, how often do they include an assessment of patients' ability to independently					
List their medications and their function?	85	12	2	1	361
Perform airway clearance without reminders/supervision?	83	12	3	1	359
Identify conditions requiring emergency care?	66	25	8	1	354
Identify their source of insurance coverage?	66	21	12	1	357
Contact their providers without relying on family members/other supports?	64	26	8	1	356
Plan for and attend clinic visits without family assistance?	63	28	7	1	358
Identify their entitlements/benefits?	43	32	24	1	350
Contact their insurer?	26	31	30	3	347
If your center performs assessments, how often do they include an assessment of whether the patient has the developmental maturity to function well in an adult-oriented system?	76	18	5	1	357
Is there a written list of desirable self-management skills and/or knowledge for transition?	Yes = 8%	No = 92%			351
Is there an explicit program within the center to foster the development of desirable self-management skills and/or knowledge for transition?	Yes = 18%	No = 82%			343

**TABLE 5 MD's Perception of CFF Transition Mandate, Stratified by Focus of Clinical Responsibilities**

Respondent's Clinical Responsibilities	Perception of Mandate (n = 179), % (n)		
	Agree	Neutral	Disagree
Pediatric care only (n = 55)	85 (47)	7 (4)	7 (4)
Adult care only (n = 66)	92 (61)	6 (4)	2 (1)
Both pediatric and adult care (n = 58)	72 (42)	7 (4)	21 (12)

$\chi^2 P = .008$ .

however, only one third of programs reported that adult care providers were present at such meetings. Almost half (46%) of programs reported "never" or "rarely" preparing a medical summary before transfer of care. Among programs that generate medical summaries in preparation for transfer of care, summaries were likely to include medication lists (98%), previous therapy (97%), and adverse effects of treatments (86%); however, they were less likely to include a history of difficulties in patient self-sufficiency in managing treatment regimens (59%) or a history of difficulties in communication with the patient or family (59%).

#### Patient Follow-up and Program Evaluation

Almost 60% of programs that transfer care to an adult clinic reported a mechanism to confirm a first visit with the adult clinic. More than 80% of all clinics reported reviewing patients' transition experiences in some manner; however, only 36% reported that there was exchange of reviews between pediatric and adult teams. A total of 35% reported that there was no routine evaluation of the transition process.

#### Self-Evaluation

On a scale from 1 to 10, with 10 representing an ideal effort, the mean self-rating of the transition process was 5.8 (SD: 2.2). In self-rating specific transition processes, the highest mean ratings were in communication between pediatric and adult teams (7.3; SD: 2.6) and coordination to maintain benefits (6.9; SD: 2.3). Institutional support for transition (5.8; SD: 2.9), needs assessment (5.7; SD: 2.5), and the provision of transition resource materials for patients and families (4.3; SD: 2.5) were scored most poorly. Respondents who reported working only with pediatric patients rated the overall transition process at their programs more highly (6.3; SD: 1.8) than those that provide care only to adult patients (6.1; SD: 2.3) and those that provide care for both pediatric and adult patients (5.4; SD: 2.3;  $P = .007$ ).

Caregivers were asked whether they supported the CFF mandate for transition services and what they anticipated that the financial impact of transition of patients would be. Overall, the mandate for transition services was strongly supported. A total of 80% of respondents "agreed" or "strongly agreed" with the mandate, and fewer than 10% disagreed. Notably, physician responses to the mandate varied significantly on the basis of the focus of their clinical responsibilities. Those

who care for both pediatric and adult patients were less supportive of the mandate (Table 5).

The financial impact of patient transition on CF centers was anticipated to be neutral for both pediatric (57%) and adult programs (51%) by the majority of respondents; however, when responses for the anticipated financial impact on pediatric versus adult programs were compared by  $\chi^2$  test on the basis of physicians' clinical responsibilities, those who care for exclusively pediatric or exclusively adult patients anticipated more positive financial impact on adult centers ( $P = .02$  and  $P < .001$ ); there was no statistically significant difference in the anticipated impact among physicians who care for both pediatric and adult patients ( $P = .20$ ).

#### DISCUSSION

This national, comprehensive survey of US CF programs elicited the perspectives of all members of the multidisciplinary CF care teams on their delivery of transition-related services. The survey captured transition experiences at 87% of all US CFF-accredited programs and included input from 448 providers. Lacking an existing, validated instrument, we constructed a survey on the basis of a conceptual model of transition by using a literature review and expert opinion. Testing of correlation coefficients suggested a strong coherence within domains and good intrarater reliability. Although interrater reliability comparing responses of individuals within centers was variable, there were not consistent trends, suggesting that input of multiple staff is helpful to construct an accurate picture of practice at a given site because experiences may vary across patients and providers.

The survey had several key findings. First, although transfer of care in CF occurs at a median age of 19 years, initial discussion of transition does not occur until a median age of 17 years, leaving a limited amount of time for patients, families, and care teams to delineate and foster key self-care skills. This age of initial discussion of transition is even older than that found from a previous survey of program directors, performed before the CFF transition mandate, which reported an average age of transition discussion of 15.9 years (range: 0–18 years).<sup>12</sup> In fact, an international survey of individuals with CF found that only 10% reported introduction of the concept of transition before the age of 15 years.<sup>16</sup> These findings all suggest that, despite a growing discussion about the importance of development of self-care skills and successful transition to adult CF care for teenagers with CF, inadequate time is usually allowed for the process. One of the first steps that CF programs that are intent on improving the transition process can make is introducing the ideas of self-care skills and eventual transition to adult care earlier in the teenage years.

Second, current strengths in the transition process and important opportunities for improved transition care were identified. Strengths include high levels of family support for and involvement in transition and caregiver attention to age-appropriate preventive care in several areas including substance abuse, smoking, and

dieting behavior; however, only half of CF programs consistently perform readiness assessments for critical self-management skills such as ability to list medications, take medication/perform airway clearance without being reminded, and contact caregiver and insurance company. Fewer than 10% of centers have a written list of desirable self-management skills. These findings suggest that there is a need for greater emphasis on the importance of developing self-management skills as a critical part of the transition process, rather than focusing solely on the transfer of care to a new team. A nationally accepted list of CF-specific self-management skills by age category would aid in making self-management and independence a more central focus of transition of care.

Even at programs that report “always” or “usually” offering health education as part of their transition process, fewer than two thirds discuss current sexual activity or fertility intention. This finding by provider report reinforces previous research that found low rates of such counseling on the basis of patient surveys. A survey of 146 adolescents who had CF and were seen at comprehensive CF centers in 5 North Carolina referral hospitals found that among the 83% who had seen their CF specialist in the preceding year, 65% had received counseling on weight and dieting but only 30% on sexuality.<sup>17</sup> This is particularly important because surveys of adult women with CF indicate that they are less likely than healthy peers to use contraception but are equally likely to be sexually active.<sup>18</sup>

One area of surprising findings from the survey was in the structural organization of transition. Almost half of programs reported “never” or “rarely” preparing a medical summary before transfer of care. More than one third of programs reported that there is no routine evaluation of the transition process. In general, although survey respondents espoused their support for transition activities, they reported a lack of institutional support for transition programs and a failure to deliver specific services consistently to all patients. This resulted in a mean self-rating of 6.2 of 10 for the overall transition process. The use of formal transition-focused visits and regular team meetings are possible ways to address these organizational issues. A summary of practical steps for improvement of transition from pediatric to adult CF care on the basis of the items with lowest scores across all transition domains is provided in Table 6.

Despite initial concerns, financial consequence of mandated transition to adult programs does not seem to be a large concern for most centers. Although pediatric caregivers were more likely to identify the financial effect of transition as being “somewhat negative,” <5% identified it as being “strongly negative.”

Finally, it is important to recognize that although there are clearly areas for improvement in the current national practices of transition from pediatric to adult CF care, the development of the CF transition of care process can be viewed as a model for other chronic pediatric illnesses with a growing adult population. To provide perspective beyond the CF experience, a national survey<sup>5</sup> of parents of youth with special health care needs found that only 50% reported any discussion with their

**TABLE 6 Practical Steps for Improvement of Transition From Pediatric to Adult CF Care on the Basis of Areas With Lowest Scores Across All 7 Transition Domains**

Patient-oriented	
Provide a written list of desirable self-management skills	
Provide a transition timeline to patients and educational materials about transition	
Schedule a visit focused on transition	
Perform a formal assessment of patient's readiness for transition, which includes assessment of ability to identify insurance and assistance program entitlements/benefits and ability to contact insurer	
Provide written information on maintaining benefits	
Assess patient's level of sexual activity and fertility/pregnancy intention	
Physician/care team-oriented	
Designate a team member who is responsible for key elements of transition	
Establish a program to foster development of self-management skills	
Develop a written checklist of age-appropriate health education items	
Develop center-specific transition resource materials for patients/families	
Prepare a written summary of the medical history for new team, which includes evaluation of patient self-sufficiency in managing treatment regimen and history of difficulties in communication with patient or family	
Contact the patient's primary care provider	
Regularly evaluate the center's transition process	

physician of their child's changing health care needs in adulthood. Among the 50% with whom a discussion occurred, 40% reported that the discussion lacked a plan for addressing those changing needs. By supporting the development of and mandating transition of care to adult CF programs, the CFF and CF caregivers have provided a model for both planning for and addressing the changing health care needs of youth who have special health care needs and reach adulthood. With minimal alteration, the survey used in this study could also be used to assess the state of transition services for a wide diversity of chronic childhood illnesses.

## CONCLUSIONS

This survey characterizes the nationwide transition to adult care experience of >85% of all individuals with CF in the United States. Several simple steps, including introduction of the transition concept to patients at an earlier age, greater focus on development of self-management skills as an essential component of the transition process, and establishment of a nationally accepted list of CF-specific self-management skills by age category, all might aid in improving the rate of successful transition of patients to adult CF care. The model of transition to adult care pioneered by the CF care community is making available to many patients with CF health care transition services that are currently unavailable to individuals with other special health care needs and can serve as a model for the numerous chronic conditions with emerging adult populations.

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