



Review article

Health Care Transition for Youth With Special Health Care Needs

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 A B S T R A C T

Purpose: Youth with special health care needs (YSHCN) increasingly live into adulthood, and approximately 500,000 U.S. youth transition from pediatric to adult health care systems annually. Through a systematic literature review, we sought to (1) determine adult outcomes for YSHCN who have no special transition interventions and (2) identify evidence for strategies that lead to better outcomes, in particular, access to adult health care.

Methods: We searched the medical, nursing, psychology, and social science literature and reviewed selected articles' reference lists. Transition experts also recommended relevant articles. Search criteria included health conditions, transition-related activities, and health care and related outcomes. We selected English-language articles published from 1986 to 2010, with an abstract, description of transition-related interventions (objective 2), and posttransition outcomes. Investigators abstracted study design, population, sample size, description of intervention, data collection methods, and findings.

Results: The search yielded 3,370 articles, of which 15 met study criteria. Although many YSHCN appear to make the transition to adult health providers successfully, some experience serious gaps in outcomes; those with more complex conditions or with conditions affecting the nervous system appear to have less good transitions. Some evidence supports introducing YSHCN to adult providers before leaving the pediatric system; one study supports using care coordinators to improve outcomes.

Conclusions: Evidence regarding programs to facilitate transition for YSHCN is inconclusive. Weak evidence suggests that meeting adult providers before transfer may facilitate posttransition access to care. We recommend additional studies with strong research designs to guide best practice in preparing YSHCN for adulthood.

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 IMPLICATIONS AND
 CONTRIBUTION

Although many youth with mild special health care needs transition successfully to adulthood, those with more complex medical conditions experience less educational and employment success. Youth with cognitive or mental health impairments have poorer transition experiences. Few programs demonstrate evidence of success in improving youth's transition outcomes.

With improved medical care and greater prevalence of chronic and disabling conditions, increasing numbers of youth with special health care needs (YSHCN) are surviving into adulthood [1]. This change in survival in childhood chronic

illness requires a change in perspective on the future for these youth. Rather than face premature death, YSHCN face adulthood with the need for preparation to take responsibility for their health care and personal and professional lives. Nearly 500,000 YSHCN in the United States make this transition to adulthood annually [2].

The Maternal and Child Health Bureau's (MCHB) focus on transition to adulthood began in 1989 with the Surgeon General's conference on transition of YSHCN [3]. This emphasis continues as one of the MCHB six core objectives. "All youth with

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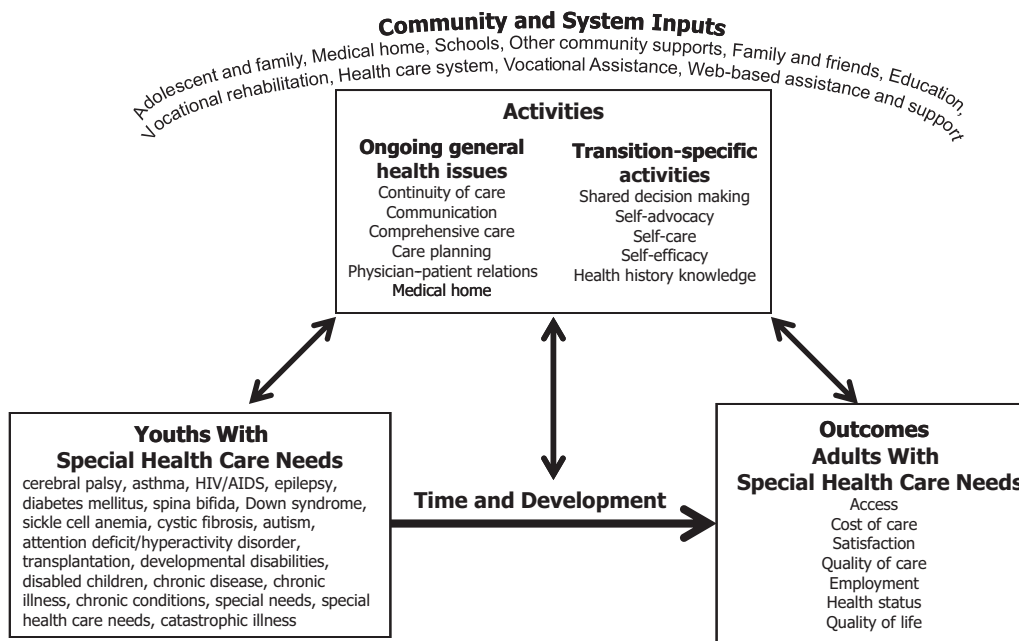


Figure 1. Logic model for transition of youth with special health care needs.

special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence” [4]. The American Academy of Pediatrics 2002 consensus statement on transition defines its goal as a process to “maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.” To achieve this goal, youths need identified providers of adult health care who understand the needs of young adults with lifelong special health care needs, the skills and knowledge to support their own care, a medical summary to provide new caregivers, ongoing primary and preventive care, and continuous health insurance [2]. Programs that facilitate transition for YSHCN should provide services that are coordinated, flexible, and chronologically and developmentally appropriate, address concerns common to all youth, and support emerging autonomy [5].

Questions about the process of transition were included in two MCHB-sponsored National Surveys of Children with Special Health Care Needs (NSCSHCN), although the assessments changed substantially from the first to the second survey. In the initial survey (2001), only 15.3% of youth aged 13–17 years met all three criteria for successful health transition: discussion with doctors about the youth’s changing needs into adulthood (met by 50%); whether providers had developed a plan for addressing the changing needs (59.3%); and whether health care providers discussed transferring the youth’s care to a doctor who treats adults (41.8%) [6]. In the 2005–2006 NSCSHCN with different criteria for the transition process, 41.2% of parents reported that youth met standards for transition (any one of first three and the fourth): (1) the doctor or other health care provider discussed changing to an adult provider (41.9%) (relevant for youth receiving care from pediatric-only providers); (2) the doctor discussed adult health care needs (62.4%); or (3) providers discussed changes in health insurance (34.1%); and (4) the doctor or other health care provider usually or always encouraged the YSHCN to take responsi-

bility for his/her care (78%) [7]. Fewer than half of youth met even these new criteria for successful transition.

We carried out a systematic literature review to examine existing evidence regarding health care transitions. In particular, we sought to answer two questions regarding transition. First, what are the general outcomes for YSHCN whose transition proceeds without special intervention? Second, what transition activities lead to better health care outcomes for YSHCN?

Methods

We developed a logic model to guide the review (Figure 1). This model contains four elements: (1) underlying special health care needs; (2) youth, family, community, and system-wide characteristics that may influence transition (e.g., schools, health insurance, health care system); (3) health transition activities; and (4) outcomes of transition including access to care, met needs, cost of care, satisfaction with care, quality of care, health status, quality of life, or access to health insurance. Health conditions, both in general and specific, were added to the model and are shown with the figure. The project advisory committee, including experts in transition, helped refine the model by expanding the health condition list, focusing the relevant outcomes, and defining the activities that lead to successful transitions.

Using the logic model to define search terms, we searched four databases: Medline, PsycINFO, Cumulative Index of Nursing and Allied Health Literature, and Social Sciences Citation Index. The initial searches combined the four elements of the logic model and were restricted to literature published between 1986 and 2010, in English, from developed countries, and including an abstract. Because the inclusion of community and system inputs too greatly limited the range of articles returned in the searches without improving the quality of the results, these terms were dropped. The searches were designed to be inclusive and so

captured many articles that did not meet the final selection criteria.

Two investigators (S.B. plus K.K., J.V., or A.K.) reviewed all searches, read all titles, read abstracts of potentially relevant articles, and identified articles for further review. A third investigator (either J.V. or K.K.) resolved disagreements between the primary reviewers. We selected articles for inclusion if they included an intervention (required for only the second study question), a comparison group (e.g., control group, matched comparison, pre-/postintervention), and an outcome (e.g., high school graduation rates, satisfaction with care, appointment with adult care provider, metabolic indicators). We also included descriptive reports from the NSCSHCN and other broad population-based surveys, articles recommended by advisory board members, and additional references from reviews and abstracted articles. This approach excluded case reports or series describing transition experiences or programs, but without interventions, comparison groups, or outcomes.

The abstracted data included study design, population (including health condition[s] and sample size), description of intervention, data collection methods, and findings. Data were recorded in an Endnote database. We did not explicitly grade the quality of the studies.

This study, a systematic review of the literature, did not require approval of an institutional review board.

Results

The search of the four databases identified 3,370 articles, of which 156 were selected for more careful review. Of the 156 articles, 13 met our methodological criteria and were included in this review. Most rejected articles were excluded for lack of posttransition outcomes. We identified three additional articles from the cited literature of various references for a total of 15. By condition group, reviewed articles described special health care needs (5), cystic fibrosis (CF) (3), developmental disability (2), diabetes (4), and congenital heart defect (1). We first review the evidence regarding the general experience of YSHCN in transition and then describe evidence about programs or activities that facilitate transition. Table 1 summarizes information about authors, publication year, study, country of origin, health conditions, intervention, research design, and direction of outcomes.

Question 1: Health care transitions without specific interventions

Several studies provide evidence that, for many youth, transition to adulthood in the absence of special intervention proceeds smoothly for some objectives but with problems for others. Some broad population-based studies report that, although some differences exist, YSHCN often differ little from their healthy peers in achieving the milestones of adult life. In a U.S. study, compared with their peers and after controlling for the mother's sociodemographic characteristics, young adults with chronic conditions (54% with asthma, 7% spinal anomalies, 6% each diabetes mellitus and rheumatoid arthritis, 5% epilepsy, and others) experienced no difference in educational achievement ($p = .61$) and no difference in self-esteem ($p < .46$). However, there was an inverse association between having a chronic condition and income that approached statistical significance at $p = .06$ [8].

A survey of young adult graduates of Kentucky's Title V program for CSHCN compared with their instate or nationwide peers

from large-scale surveys found several differences in outcomes, both positive and negative. Title V graduates were more likely to report a usual source of care (83% vs. 73.3%), less likely to lack health insurance (25%, comparable with their preadulthood rate, vs. 38.7% for peers in Kentucky), but only 72% completed high school or higher education compared with 85.9% nationally, and 29% were idle (not working, in school, or caring for children) compared with 5.7% of female and 3.3% of male peers [9].

A report using National Longitudinal Study of Adolescent Health data found that, compared with their peers, youth with childhood cancer, heart disease, diabetes, or epilepsy had no difference in the odds of marrying, having children, living with parents, or in the quality of their romantic relationships. However, they had lower odds of graduating from college (adjusted odds ratio [AOR]: .49; 95% confidence interval [CI]: .31–.78) or being currently employed (AOR: .56; 95% CI: .39–.080), but higher odds of receiving public assistance (AOR: 2.13; 95% CI: 1.39–3.25). In linear regression models, youth with childhood onset of chronic conditions had incomes that were \$5,157 (95% CI: –7,977, –2,336) lower than their peers [10].

A general population survey from Finland in 1983, with follow-up in 1989 at age 22 years, found that young adults with serious conditions (e.g., asthma, diabetes, seizure disorder, kidney disease, cerebral palsy, and polyneuropathy) compared with peers with no health conditions, experienced higher adjusted depression scores ($p < .05$), but had no differences in educational achievement, few differences in social development (women with chronic conditions were less likely than healthy comparisons to live with their parents and more likely to live with a partner or spouse [p values $< .05$]), and reported no differences in health behaviors of smoking and alcohol use [11].

In a U.S. study of young adults with developmental disabilities, the odds of being neither competitively employed, a student, nor a caregiver were greatest for those with severe mental retardation and those with multiple impairments. Having a limitation in activities of daily living or in instrumental activities of daily living was associated with decreased likelihood of young adults achieving appropriate adult social roles. Young adults with severe mental retardation were the least likely to achieve adult social roles. (All p values $\leq .05$) [12] Similarly, a national survey of young adults with developmental disabilities found that 80% were very or somewhat satisfied with their lives. In multivariate models, decreased general life satisfaction was associated with idleness and with reporting only housework as an activity ($p < .001$). In addition, those with mental health disabilities or head injuries reported lower general life satisfaction ($p < .001$) [13]. From these findings, it appears that youth whose special health care needs involve mental health, developmental disabilities, or severe mental retardation face extra challenges in achieving the expected milestones of adult life.

Question 2: Evidence for transition outcomes after interventions

Cohort studies with comparison groups. We identified two cohort studies that compared outcomes for young adults, some of whom participated in transition or support programs. One U.S. study described results of a CF program that introduced youth and their families to adult clinic providers before the actual transition. The 58% of families (not randomly assigned) who met the adult team before transition reported significantly fewer concerns about leaving pediatric providers ($p < .004$), fear of infection ($p < .04$), admission to the adult hospital floor

Table 1
Summary of interventions, research designs, and outcomes

Author, publication year (country, condition)	Intervention					Research design					
	None or not described	Meet adult providers	Multidisciplinary team	Counseling	Transfer to adult providers	Randomized controlled trial	Cohort with comparison	Descriptive cohort	Pre-/poststudy design	Large-scale survey with comparison	Large-scale survey without comparison
Bent et al, 2002 (England, SHCN)			X				X				
Blomquist, 2007 (USA, SHCN)	X									X	
Boyle et al, 2001 (USA, CF)		X					X				
Braun et al, 2006 (USA, DD)	X									X	
Busse et al, 2007 (Germany, diabetes)					X				X		
Bussing and Aro, 1996 (Finland, SHCN)	X									X	
Gortmaker et al, 1993 (USA, SHCN)	X									X	
Holmes-Walker et al, 2007 (Australia, diabetes)				X					X		
Kipps et al, 2002 (England, diabetes)		X							X		
Maslow et al, 2010 (USA, SHCN)	X									X	
Nasr et al, 1992 (USA, CF)		X					X				
Reid et al, 2004 (Canada, congenital heart defects)					X			X			
Salkever, 2000 (USA, DD)	X										X
Salmi et al, 1986 (Finland, diabetes)					X				X		
Steinkamp et al, 2001 (Germany, CF)		X							X		

+ indicates positive results.
 – indicates negative results.
 ± indicates mixed results.
 = indicates no difference.
 SHCN = special health care needs; CF = cystic fibrosis; DD = developmental disability.

($p < .02$), and decreased quality of medical care ($p < .002$) after transition [14].

Young adult social support teams, offered at two programs in England, were compared with two geographically dispersed programs that offered usual services. After adjusting for pain and fatigue, physically disabled youth with complex neurological conditions in England who lived near and sought care at either of these two sites with young adult teams were 2.54 times (95% CI: 1.30–4.98) more likely than peers who were served at sites without these teams to participate in society (as measured by the London Handicap Scale that measures physical and economic self-sufficiency, use of leisure and work time, and social integration) [15].

Pre-/poststudy design. Researchers from Australia reported results of a young adult clinic for youth aged 15–25 years with diabetes. A diabetes educator oversaw the program and reminded youth of upcoming appointments and followed up after missed appointments. The program also provided after-hours phone consultation. On average, youth’s HbA_{1c} level dropped .13% per visit for the first four clinic appointments ($p = .01$) over approximately 2 years. Hospital admissions for diabetic ketoacidosis dropped to approximately two-thirds of the rate before implementation of the program ($p < .05$), but the number of diabetic ketoacidosis readmissions (hospitalizations within 12 months of another hospital stay) remained unchanged. With program implementation, the length of hospital stay did not change overall, but it was reduced by 3.6 days for readmissions ($p = .02$). Cost savings from forgone hospital days offset the extra program costs [16].

In a multisite report from England in which half the sites introduced youth to adult diabetes specialists before transition,

youth who met these physicians had more regular clinic attendance 2 years after transition. Youth in these sites reported greater satisfaction with the transition than their peers in sites without this opportunity ($p < .014$). For youth seen after transition at hospital clinics, metabolic control appeared unchanged before and after transition. By clinic site, average HbA_{1c} level ranged from 9.7%–10.6% pretransition to 9.8%–10.0% after transition ($p = 1.0$) [17].

In Germany, where by regulation, youth must transfer to adult care by age 18 years and are supposed to have advice about new providers, young adults with diabetes (average age 22 ± 2.4 years) were surveyed regarding their transition experiences. They reported lower annual clinic attendance after transition, dropping from 8.5 ± 2.3 visits per year to 6.7 ± 3.2 ($p < .05$), and mixed perceptions of satisfaction with care, with 43.6% preferring pediatric care, 42.2% reporting no difference in care, and 13.9% more satisfied with care in the adult system. Receiving guidance in identifying adult providers was viewed as helpful. Metabolic control was unchanged after transition among the youth whose providers reported results to the researchers: HbA_{1c} levels $8.5\% \pm 1.5\%$ pretransition versus $8.3\% \pm 1.6\%$ post-transition ($p = .44$) [18]. Unlike this German study, a report from Finland described improved metabolic control of diabetes after transition, from $11.2\% \pm 2.2\%$ for HbA_{1c} to $9.9\% \pm 1.7\%$ ($p < .001$), with greater improvements observed for females than males. At the time of this report, youth in Finland were transferred to adult care at age 15 years [19].

CF programs have developed strategies to facilitate the transition of youth from pediatric to adult care providers. In particular, many programs report introducing youth to adult CF care providers before initiating the transition to the adult clinic. One German program, before opening an adult CF clinic, integrated

Table 1
Continued

Outcomes								
Employment	Quality of life	Access	Insurance	Mental health	Education	Satisfaction with care	Outcomes of care	Quality of care
–	+	+	+	+	–			
–	–	–				±	=	
	=			=	=			
				=	=			
		+					+	
		+				+	=	
–	=				–			+
		+						
	+							
						+	+	

the adult pulmonologist into the pediatric clinic where she saw all patients aged ≥ 18 years [20]. A Michigan program assigned first-year internal medicine pulmonary fellows to 17-year-old CF patients for 1 year in the pediatric clinic. During the second year, the trainee continued to provide the patients' care but in the adult clinic. Patients reported that this two-step program made the transition easier [21].

Programs that serve youth with congenital heart defects also attempt to connect youth with adult providers. A Canadian program found that youth whose medical records included a recommendation for follow-up care to an adult cardiac center were 3.5 times as likely as others to believe that their adult care should be at the center. Being seen at the adult center was associated with the documented recommendation and the youth's belief that adult care should be at the center (odds ratio: 3.64; 95% CI: 1.34–9.90) [22].

Discussion

This systematic review addressed two questions—the success with which YSHCN make the transition to young adulthood and the evidence for what interventions may enhance transition, especially to adult health care. Achieving educational goals, securing employment with health insurance, developing friendships and loving relationships, and establishing independent living are among the milestones expected of all young adults. Those with special health care needs have the added challenge of managing their more complicated health care transitions, understanding their health histories, and assuming responsibility for their own health care, including self-advocacy, self-care, appointment making, and adherence to treatment.

According to population-based studies, transition appears to proceed smoothly for many YSHCN, especially for those who have, on average, milder conditions with no limitations in activities or cognitive impairment. Their transition to adulthood is in most cases similar to that of their peers without special health care needs. However, youth with more complex medical conditions, although often experiencing social and mental health outcomes that are comparable to their peers, seem to have generally lower educational achievement, more limited work experience, and lower incomes; youth with multiple health problems or severe cognitive or mental health impairments appear to experience more significant difficulty transitioning from childhood to adulthood. Furthermore, some anecdotal reports or studies using qualitative methods describe significant problems for many [23,24], and YSHCN from racial/ethnic minorities have problems with access to care or gaps in health insurance that likely lead to poorer transition outcomes [25]. For some youth, transition to adult care leads to poorer quality health services and subsequently poorer health. This review provides more information about how well YSHCN do in transition and much less about the programs that may help. Little evidence has been published [26], and what little evidence that exists appears to indicate that providing some direct contact with adult health providers before leaving the pediatric system may enhance transition, especially in improving likelihood of follow-up, some metabolic markers (in diabetes), and satisfaction with adult care. At least one study suggests that having a coordinator focused on aiding transition may also help reduce unnecessary hospital admissions, thereby reducing costs.

Clinicians and families agree that transition is a lengthy process rather than an abrupt event. The steps in this process include

creating a written transition plan for health care and a medical history summary [2]; with the help of the pediatric caregivers, identifying appropriate adult health care providers who are willing and knowledgeable to care for the youth's special needs [27]; educating youth to understand their health conditions and to assume responsibility for their care [28]; developing strategies for securing health insurance [29]; and planning for the future in terms of education and employment [30]. Programs that support these activities may achieve better outcomes for youth.

In addition to support for parents and youth in changing from pediatric to adult health care providers, it is possible that pediatric caregivers need training to facilitate youth's transition [31] and support in letting go of patients with whom they have developed close working bonds [32]. Likewise, adult care providers report a need for training regarding medical care of YSHCN to avoid mismanagement of care [33]. They also cite concerns about their ability to provide needed psychosocial supports (e.g., care coordinators, social workers) that are thought to be more available in pediatric settings and the financial constraints from payers that may prevent them from spending sufficient time with newly transitioned youth [34]. Finally, as the supply of adult-oriented primary care physicians shrinks, YSHCN, their parents, and their pediatric providers will face even more barriers to securing appropriate adult-focused care [35].

The literature evaluating programs to enhance transition for YSHCN has several limitations. The research designs examining transition programs were weak and prevented attributing causality with certainty. Our search found no randomized controlled trials or similar strong study designs. Absence of hypotheses, lack of control groups, nonrandomized protocols, site- or provider-based biases in natural experiments, small numbers of study participants with little power to detect differences, and use of surveys whose validity and reliability are not described are among the many design flaws. In addition to correcting these weaknesses, the addition of longitudinal follow-up (a minimum of 1 year posttransition) to determine relevant outcomes for youth would strengthen research on programs to facilitate youth's transition.

Most research has been conducted outside the United States. Differences in the organization of health services, and especially access to health insurance coverage, may limit the generalizability of lessons from other countries to the United States. The passage of health care reform in the United States allows youth to continue coverage under family plans to age 26 years and may help young adults to enroll in health insurance and experience fewer financial barriers to accessing needed health care. Finally, we identified no research meeting our criteria that came from primary care or medical home practices. This absence precludes the generalizability of findings to these settings. The growth in medical homes may lead to more research on transition in the context of a medical home.

Limitations of the study

Our primary research method, conducting systematic searches of selected literature databases, may have missed relevant articles. To help guard against this, our search strategy was purposefully expansive and identified many articles that did not meet our criteria. In addition, we limited the scope to transition to adult health care providers rather than include the wide range of transitions that YSHCN must undergo—in education, housing, transportation, and social and emotional life.

Conclusions

Most YSHCN appear to have successful transitions to adult health care. Certain conditions put youth at risk for poorer transition, and these groups may merit more attention in efforts to enhance transition. Although most of the few studies finding positive effects of programs to enhance transition come from non-U.S. sites, they may merit adoption in the United States, as their findings (introduction to adult care providers or the use of care coordinators) may have general applicability with the potential to yield positive outcomes.

The dearth of evidence regarding transition for YSHCN indicates the need for rigorous research into the elements of effective programs to facilitate transition to adulthood. Hypothesis-driven studies with rigorous methodologies, randomization to intervention and control groups, standardized study instruments with demonstrated validity and reliability, blinded raters of outcomes, and longitudinal follow-up are needed to replace the largely anecdotal program reports of client satisfaction with services.

Determining the key elements of transition programs that lead to better outcomes will contribute to the design of efficient models of care. After these elements are identified, policymakers and practitioners will need to consider various questions regarding their implementation. For instance, are nonphysician transition coordinators needed to implement programs, and, if so, how can their services be reimbursed under the evolving U.S. health care system? Is a referral to an adult care provider sufficient to ensure youth's ongoing care, and, if so, how can general pediatricians make such referrals when few general internists accept YSHCN into their practices? A health care system that devotes substantial effort and resources to securing optimal outcomes for children and youth with special health care needs should ensure that the successes persist into adulthood.

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