



Health Care Transition
for Youth with Disabilities and
Chronic Health Conditions
A Rhode Island Policy Brief



Table of Contents

INTRODUCTION	1
BACKGROUND ON HEALTH CARE TRANSITION	1
DEVELOPING HEALTH CARE TRANSITION POLICY	2
HEALTH CARE TRANSITION TODAY	3
BARRIERS TO HEALTH CARE TRANSITION PLANNING	4
HEALTH CARE TRANSITION EFFORTS IN RHODE ISLAND	5
OPPORTUNITIES FOR HEALTH CARE TRANSITION PLANNING	7
RECOMMENDATIONS FOR SUCCESS	8
REFERENCES	

INTRODUCTION

The increasing number of youth with disabilities and chronic health conditions surviving into adulthood has necessitated a shift in the approach to educational, health, employment, and independent living services. The emphasis has shifted toward ensuring inclusion and full participation of individuals with disabilities and chronic health conditions in education, meaningful employment, and community living.¹ To achieve these goals as adults, youth with disabilities and chronic health conditions may require support and services to help them transition in all aspects of their adult lives, including employment, independent living, and health care. The receipt of adequate health care is a vital component of this vision. Health affects all aspects of life—school, community, and job success are all associated with health.²

Health care transition is the process of changing health care providers (for example, from pediatric health care to adult health care).

BACKGROUND ON HEALTH CARE TRANSITION

Advances in technology, treatment, and preventive interventions for youth with disabilities and chronic health conditions have had great success in the past few decades. Consequently, more of these youth are living into adulthood and are leading longer, more fulfilling lives. The Maternal and Child Health Bureau (MCHB) of the United States Department of Health and Human Services (DHS) defines children with special health care needs as those who “have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”² Based on recent estimates, it is expected that more than 90% of children born today with a chronic or disabling health condition will live more than 20 years.³ It is estimated that approximately 500,000 children with special health care needs will turn 18 each year.³

Thirteen percent (9.4 million) of youth in the United States and 14% (35,265) of youth in Rhode Island under the age of 18 have special health care needs.

All youth, including those with disabilities and chronic health conditions, require age-appropriate health care services. Often, a pediatrician is not the appropriate provider for a youth with adult health care needs, including reproductive health care and screenings for adult risk factors. Additionally, the goal for youth with disabilities or chronic health conditions—as with all youth—is that they will grow into adulthood with the ability to independently manage their health care.² To do this, they must understand their health needs and be able to participate in health care decisions. These goals are best achieved through effective transition from pediatric to adult health care when it is developmentally appropriate based on the youth’s needs.² Given the importance of health care to the overall well-being of individuals with disabilities and chronic health conditions, the

transition process from one provider to another needs to be seamless so that the youth does not experience a gap in health care. Advance planning assures the greatest success of seamless transition.

DEVELOPING HEALTH CARE TRANSITION POLICY

In response to these issues, health care policymakers recognized in the late 1980s – early 1990s that there was a significant gap in the policies and services available to help youth with disabilities and chronic health conditions transition from pediatric to adult health care. In 1989, the United States Surgeon General issued a report titled *Growing Up and Getting Medical Care: Youth with Special Health Care Needs*, which addressed the needs of youth, families, and health care providers with respect to health care transitioning.³ Health care transition was researched and discussed further in the next decade, and several policy statements were issued regarding the need for and challenges to transition planning.³ Federal legislation affecting youth with disabilities and chronic health conditions also underwent reform during this decade.⁴

In 1996, the MCHB started its Healthy and Ready to Work (HRTW) Initiative to research and address health, education, and employment transition issues facing youth with disabilities and chronic health conditions.¹ In 2000, the HRTW Transition Workgroup set a 10-year agenda with goals focusing on system development and youth empowerment.⁴ These goals were incorporated into *Healthy People 2010*—a plan that defines health goals for the country in the next decade.

THE CENTRAL ROLE OF PHYSICIANS

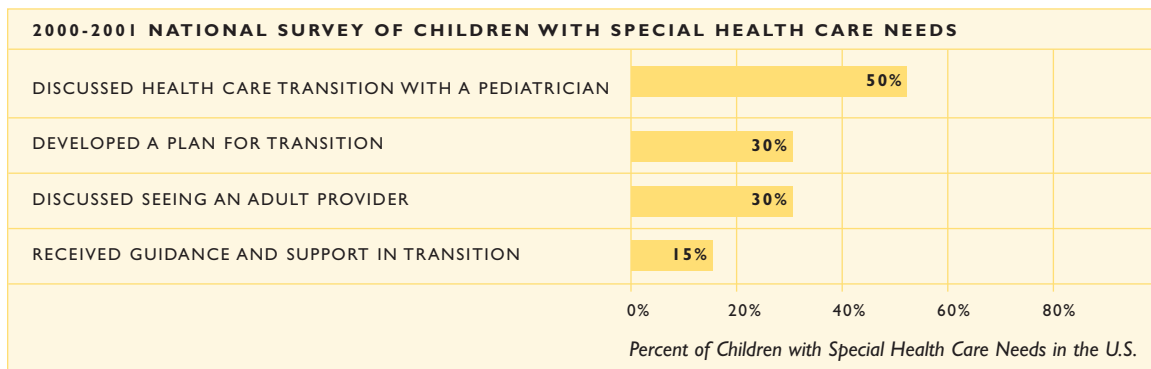
In 2002, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians–American Society of Internal Medicine issued a consensus statement focusing on the responsibilities of physicians in transition planning for youth with disabilities and chronic health conditions.⁵ The statement emphasized that physicians must play a key role in helping youth transition to adult health care. Ideally, transition planning should be a team effort between the youth, the youth’s family, and the youth’s health care providers, including the pediatrician, the adult primary care provider, and specialists. Often, the transition of care for the youth requires coordination amongst several providers (primary care and specialty care). The pediatrician is a good focal point of coordination because he or she often has a close, long-standing relationship with the patient, and therefore is the most familiar with the patient, the patient’s history and abilities, the complexities of the patient’s condition, and the patient’s and family’s priorities.⁵

The consensus statement presented the following initial goals for providers.⁵ Providers should:

1. Understand the rationale for transition from pediatric to adult health care.
2. Have the knowledge and skills to facilitate that process.
3. Know if, how, and when transfer of care is indicated.

HEALTH CARE TRANSITION TODAY

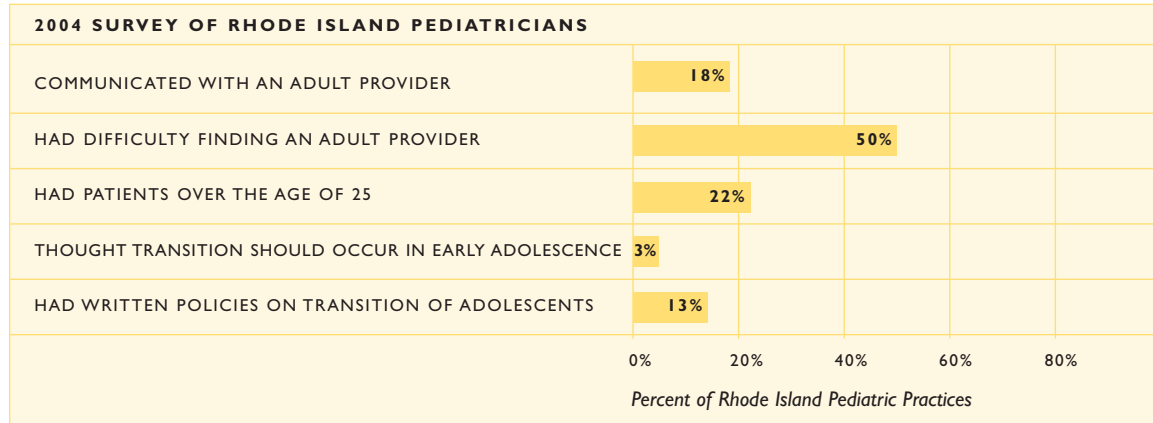
Studies show that many primary care pediatricians have not yet adopted health care transition planning into their practices. In a study conducted in 1995, 126 interdisciplinary transition programs were surveyed to identify models and best practices.⁶ The study found that most existing transition programs only target specific conditions, and few were based on primary care models. Data from the 2000–2001 National Survey of Children with Special Health Care Needs, conducted by the National Center for Health Statistics, indicate that not much progress was made in the adoption of health care transition planning.^{7,8} Only 30% of youth surveyed had developed a health care transition plan,⁸ and only 15% received guidance and support for the transition process.⁷



A survey of Rhode Island pediatricians was conducted in 2004 to determine the status of health care transition processes from the perspective of Rhode Island primary care pediatricians.⁹ Results indicated that few practices had written policies on transition of youth to adult health care. Most pediatricians stated that transition planning should start approximately one year before the transition process; very few stated that it should start in early adolescence (as stated in the American Academy of Pediatrics guidelines). Twenty-two percent (22%) of practices had patients over the age of 25, and all of these patients had special health care needs. Half of the primary care pediatricians surveyed reported having difficulty finding adult care for youth with special health care needs. Some practices were able to transfer their patients to adult-oriented providers within the practice, and some planned to continue care because of an ongoing relationship with the patient. Other practices

discontinued care without providing any transition services. Few pediatricians communicated with the adult provider after a transfer had occurred.

BARRIERS TO HEALTH CARE TRANSITION PLANNING



As the studies cited above indicate, many primary care pediatricians have not yet adopted health care transition planning into their practices. The literature has cited several key barriers to health care transition planning, including the following important issues:

SYSTEM BARRIERS

- » *Lack of adequate insurance coverage:* Youth with disabilities and chronic health conditions often require a wide range of services. Many insurance policies deny or limit services to young adults and adults with disabilities and chronic health conditions.³ For example, having a pre-existing condition precludes many youth from access to health insurance after they age out of coverage under their parents' insurance.¹⁰ In addition, many youth with disabilities and chronic health conditions do not have employer-sponsored insurance due to lack of employment.³ Public insurance may be available to many families, but it is often subject to eligibility requirements and periodic review.¹¹
- » *Lack of availability of qualified adult providers:* Families and pediatricians express difficulty finding adult primary care providers with adequate experience or depth of knowledge of childhood onset conditions,³ due in part to the limited training that adult health care providers receive on these conditions.¹⁰
- » *Differences in services between pediatric and adult settings:* Many youth and their families view the system of services in adult-oriented settings to be insufficient. Oftentimes, pediatricians deal with multidisciplinary teams, whereas many adult providers do not coordinate with other providers and do not deal with multiple specialties in one setting.³

- » *Absence of referral networks:* Pediatricians often do not know which adult primary care and specialty providers are qualified to provide the services that the youth needs.^{3,6}
- » *Lack of institutional support for providers:* Physicians report that, typically, time spent on transition training and planning is not reimbursed.⁶

PERSONAL/INDIVIDUAL LEVEL BARRIERS

- » Low level of awareness of the need for advance planning among youth and their families.⁸
- » Patients', families', and pediatricians' reluctance to lose their close, long-standing relationship.^{3,10}
- » Fear, anxiety, or ambivalence about the transition to the adult health care system.^{3,6}
- » Environmental or family stresses and competing priorities.¹⁰
- » Severity of the youth's disability and his or her level of maturity and understanding.¹⁰
- » Distorted perception of potential patient outcomes.¹⁰

HEALTH CARE TRANSITION EFFORTS IN RHODE ISLAND

Several statewide efforts aim to improve transition outcomes for youth with disabilities and chronic health conditions in Rhode Island. The Rhode Island Department of Health's Office of Families Raising Children with Special Health Care Needs (the Office) and the Rhode Island Children's Cabinet have identified health care transition of youth with disabilities and chronic health conditions to adult health care as a priority area. Through the Healthy and Ready to Work component of Title V and the United States Centers for Disease Control and Prevention's grant to Rhode Island's Disability and Health Program, the Office has implemented a three-pronged approach to addressing this issue, including a comprehensive statewide needs assessment, family/youth outreach and education, and health care provider training.

NEEDS ASSESSMENT

The Office is in the process of conducting a comprehensive needs assessment to further understand the transition process in Rhode Island. Findings from this assessment will be used to shape the outreach, education, and training efforts for youth, guardians, and providers. In 2005, the Office administered a survey of all practicing pediatricians (>60% response rate) in Rhode Island. The Office plans to administer additional surveys to family physicians and internists to gain their perspective on the transition process and to determine their willingness to accept transitioning youth with disabilities and chronic health conditions as an important part of their roles. In addition, the Office, in partnership with the Rhodes to Independence (Medicaid Infrastructure Grant), will conduct a series of focus groups with youth with disabilities and chronic health conditions and their guardians to understand their perspectives.

FAMILY/YOUTH OUTREACH AND EDUCATION

Rhode Island currently provides many materials to families and youth about the transition process. The Office has developed a comprehensive resource guide for youth, their families, and the professionals who work with them concerning health care transition. Along with several state and community partners, the Office will develop a series of materials designed to elevate youth and family awareness of the importance of health care transition and to support them through the process. The materials will include a general brochure highlighting the health care transition process, a transition checklist, and a portable medical summary to allow the transfer of pertinent medical information to adult providers. Through its partnerships, the Office also offers a variety of community-based trainings for youth with disabilities and chronic health conditions and their families. The Office will employ a youth with a disability and a special needs advocate who will provide health care transition resources and consultation to youth, families, and professionals.

PROVIDER TRAINING

Using the findings from the needs assessment, the Office will provide a series of trainings for both pediatric and adult primary care providers. The trainings will be delivered through pediatric, family medicine, and internal medicine grand rounds at each Rhode Island acute care hospital. The Office will offer these trainings through the Rhode Island Academies of Pediatrics, Family Medicine, and the College of Physicians. Providers will also be part of the materials development process for youth and their families.

OTHER HEALTH CARE TRANSITION INITIATIVES

- » Neighborhood Health Plan of Rhode Island (NHPRI), the State's largest Medicaid managed-care plan, is now transitioning youth at age eighteen from NHPRI's children's system into their adult system. As part of this process, they will facilitate youth's transition into the adult service delivery system. The Office plans to support NHPRI through advisory committee membership, identification of adult primary and specialty care providers, and outreach to youth and their families concerning health care transition.
- » The Department of Education (DOE) operates regional transition centers to assist families and professionals in accessing educational and vocational resources and coordinates the Rhode Island Transition Council.
- » The Department of Children, Youth and Families (DCYF) is conducting an evaluation of the transition process for youth with behavioral health issues.
- » Community partners, including the Rhode Island Parent Information Network (RIPIN), the Sherlock Center for Disabilities, and the Rhodes to Independence, are educating youth, parents, and professionals about transition options.

- » The Department of Human Services (DHS), through the Office of Rehabilitation Services, provides a variety of vocation services to transitioning youth with disabilities and chronic health conditions. In addition, DHS has committed additional resources towards transitioning youth with disabilities and chronic health conditions from the children’s Medicaid system to the adult system.

OPPORTUNITIES FOR HEALTH CARE TRANSITION PLANNING

Research and current program efforts have revealed the following important opportunities for promoting health care transition planning:

SYSTEM OPPORTUNITIES

- » *Differences in services between pediatric and adult settings:* While youth and their families may believe that they receive higher quality care from their pediatricians than they would from an adult provider, it is important to recognize that a pediatric setting lacks the essential adult-focused primary and preventive services that most adults need to stay healthy.³ Additionally, youth must move to adult health care because the system of pediatric health care is always under pressure to allow room for new patients.³
- » *Public health insurance:* A few public health insurance programs are available to help individuals with disabilities and chronic health conditions obtain health insurance, including:^{10,11}
 - ~ *Supplemental Security Income (SSI):* SSI is a federal program that provides monthly cash benefits from tax revenues to low-income individuals over 65 and to those who are blind or have other disabilities.¹² The program also offers “work incentives” that provide benefits and health care coverage while individuals seek employment.¹³
 - ~ *Medicaid Buy-in:* The Sherlock Plan is a program that allows individuals with disabilities who work, but do not qualify for Medicaid because of the income criteria, to buy into Medicaid.¹⁴

PERSONAL/INDIVIDUAL LEVEL OPPORTUNITIES

- » Youth’s desire for developmentally-appropriate services and to be seen as adults.³
- » Youth’s desire for privacy and confidentiality, which are not available in a pediatric setting.³
- » Provider’s desire to follow best practices for their patients based on recommendations of sentinel organizations.

RECOMMENDATIONS FOR SUCCESS

Following is a summary of recommended actions that should be taken to facilitate successful healthcare transitions for youth with disabilities and chronic health conditions.

1. SYSTEM LEVEL REFORM TO PROMOTE THE HEALTH CARE TRANSITION PROCESS:

- a. *Successful models* for facilitating seamless health care transition for youth with disabilities and chronic health conditions to adult health care are needed to drive change and progress in this area.³ Successful models must use a family-centered, culturally-competent approach to health care for youth with disabilities and chronic health conditions, along with a high-quality relationship between the youth, family, and provider. The Medical Home serves as one good model for family-centered care.⁶ Other approaches could include training programs for medical students and residents that emphasize the development of collaborative relationships with families through home and community visits.⁶
- b. *Adequate health insurance* should be available to all youth with disabilities and chronic health conditions.¹¹ Additionally, partnering with health care plans could provide valuable links between pediatric and adult care providers.⁸

2. PEDIATRIC AND ADULT PROVIDER EDUCATION AND TRAINING:

- a. Efforts must be made to *raise awareness of pediatric and adult primary care providers* on the issue of health care transition of youth with disabilities and chronic health conditions, including current recommendations, successful models, and available resources.
- b. *Training of pediatric and adult providers* is required to develop competencies in transition planning, including dealing with the psychosocial and behavioral issues of youth with disabilities and chronic health conditions.⁶

3. FAMILY/YOUTH EDUCATION AND EMPOWERMENT:

- a. *Youth with disabilities and chronic health conditions and their families require education* about the importance of health care transition. This may include a change in expectations so that youth, families, and providers all view transition from pediatric to adult health care as a necessary and natural step in the development of youth with disabilities and chronic health conditions.³
- b. *Youth with disabilities and chronic health conditions and their families should be empowered* to participate in—and even to take charge of—the transition process. Pediatricians play an important role in reinforcing positive attitudes and encouraging appropriate transitions.³

4. OTHER POINTS TO TAKE INTO CONSIDERATION WHEN ENGAGING IN TRANSITION PLANNING:

- a. *Transition teams should recognize that transition is a complex, multi-faceted process* rather than a single event.^{3,6} It involves all aspects of adult life, including employment and independent living. Health care transition planning should be approached in this context. Transition plans should be flexible and individualized, and they should anticipate change in the youth's condition and needs.³
- b. *Appropriate youth health care does not necessarily entail a change in health care providers.* Some youth with disabilities and chronic health conditions may prefer to stay with their pediatrician if the pediatrician is comfortable dealing with adult health issues. Others may want to transition to an adult primary care provider, and still others may prefer a team of pediatric and adult-oriented providers.^{3,10}
- c. *Transition planning should occur early in adolescence* for most patients to allow for change and adjustment. Transition is more difficult for those with severe functional limitations or complicated conditions.³ By age 14, a written health care transition plan should be created, including what services are needed, who will provide them, and how they will be financed.⁵
- d. *Youth and families should be encouraged to develop and maintain a portable, accessible, and up-to-date medical summary* that will allow for successful transition into adult health care.⁵

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