



THE HSC HEALTH CARE SYSTEM

**The HSC Foundation**

---

# Advancing Health Care Transition: Multi-Stakeholder Roundtable Report

*December 2012*

## Overview

Health care transition is a process that all young adults must master so they can make appropriate health care decisions. Health care transition is a two-fold process that includes the following: a) Moving from a pediatric-centered to an adult-centered health care system and b) Acquiring the necessary skills to self-manage their health and health care.

In the summer of 2012, The HSC Foundation, in partnership with Physician-Parent Caregivers (PPC) and the Institute for Educational Leadership (IEL), hosted a model multi-stakeholder roundtable to discuss how to advance health care transition in an era of post-health care reform, dwindling medical resources, and a struggling economy. The Roundtable discussion topics included: 1) Meeting the health care needs of youth and young adults with chronic conditions and disabilities; 2) Transformation of primary care in health care transition; and 3) Improving the health care workforce for health care transition.

### *Authoring Organizations:*

*The HSC Foundation*

*Physician-Parent Caregivers*

*Institute for Educational*

*Leadership*

### **The HSC Foundation**

---

2013 H Street, NW, Suite 300  
Washington, DC 20006

---

**Tel:** 202-454-1220

[www.hscfoundation.org](http://www.hscfoundation.org)



## Introduction

Successful transition from adolescence to young adulthood optimizes outcomes for post-secondary education, social relationships, independent living, rewarding careers, and economic stability.

Transition is a normal phase of growth and development that is marked by graduating from high school, moving to college, and/or looking for work. Most young people and their families are unaware of the complexity of this process, as most facets are seamlessly addressed by current systems, such as schools, parent-teacher associations, afterschool and county activities, employment agencies, and pediatrics. Young people who are vulnerable—including those with chronic health conditions, disabilities, in foster care, poverty, or the juvenile justice systems—require targeted attention and programs. Federal statute, the Individuals with Disabilities Education Act (IDEA), creates an interagency transition process that is housed in the education system. IDEA covers students with disabilities, but does not do justice for the subset of students with chronic health conditions. Health care transition (i.e., chronic condition management) is a prerequisite for these students if they are to succeed in any other life area.

Health care transition is a process that all young adults must master so they can make appropriate health care decisions. Since young adults with chronic conditions interact with the health care system more frequently, it is imperative to ensure that they have the necessary knowledge and skills to advocate for and take care of themselves.

Health care transition is not a new concept. Surgeon General Koop first addressed this issue in 1989. The American Academy of Pediatrics, The American Academy of Family Physicians and the American College of Physicians published a consensus statement with a call to action for health care transition in 2002. In 2011, these three medical associations published a joint clinical report for health care transition and pointed out that little progress had been made in the past 20 years.

On July 24, 2012, the HSC Foundation, in partnership with Physician-Parent Caregivers (PPC) and the Institute for Educational Leadership (IEL), provided support for and hosted a model

Health care transition  
is a process that all  
young adults must  
master so they can make  
appropriate health care  
decisions.

The current health care system is overwhelming and confusing even for those who are savvy, educated, and familiar with the system.

multi-stakeholder roundtable to discuss how to advance health care transition in an era of post-health care reform, dwindling medical resources, and a struggling economy.

## Background

The current health care system is overwhelming and confusing even for those who are savvy, educated, and familiar with the system. While insurance promises access to care, it does not guarantee access to medical providers, safe care, quality care, or freedom from medical debt. Medical debt is the number one cause of all bankruptcies, accounting for three in five cases (Collins, 2012). Almost three in ten young adults who have continuous coverage delay or forego care because of costs and a similar proportion are burdened with paying medical debt over time. Medical debt is devastating for young adults, forcing them to make major life sacrifices:

- 70% accrue debt that they struggle with or cannot pay;
- 46% exhaust their personal savings;
- 28% cannot pay for basic living expenses (rent, heat, food, etc.);
- 31% delay education and career plans;
- 33% take credit card debt;
- 32% struggle to pay loans and tuition payments; and
- 7% turn to their parents for financial assistance (Mangan, 2013).

Young adults with chronic conditions are disproportionately affected, struggling with unmet medical needs that interfere with education, employment, and their ability to earn.

Health care transition is critical for young people who have chronic health conditions and/or disabilities.

- Those with chronic conditions require seamless, continuous, coordinated, comprehensive chronic condition management to prevent avoidable emergency room visits, hospital stays, medication changes, missed college or work, sick days, social growth and participation, and other opportunity costs.
- Those with disabilities need to transition to an adult system of care that is competent in caring for young people with disabilities, including those with intellectual, developmental, and physical disabilities.

Health care transition is a two-fold process that includes the following:

1. Moving from a pediatric-centered to an adult-centered health care system; and
2. Acquiring the necessary skills to self-manage their health and health care.

The second face of health care transition, mastery of managing self-health and health care, must be developed by medical professionals in partnership with young people and their families. Too often, this part of the process is neglected. Developmentally appropriate health self-management is the cornerstone for successful health care transition.

Health care transition for young people with chronic conditions and disabilities is overlooked by the three following systems:

- Health care system: Adult-centered physicians and hospitals do not have the knowledge, skills, and capabilities to provide quality care for adults with childhood-onset chronic health conditions and disabilities;
- Educational system: Traditional transition for youth with disabilities fails to include health care transition. Traditional transition occurs as an interagency process that begins in the school system through IDEA; and
- Policy systems: Children with special health care needs (chronic conditions and disabilities) are recognized as a priority population by the federal government—such as the Maternal and Child Health Bureau, Health Resources and Services Administration at the U.S. Department of Health & Human Services—but not when they grow up into young adults. Young adults with chronic conditions and disabilities are not recognized as a priority population anywhere in the federal policymaking arena. Thus, they do not have a home in any federal agency and the United States has no federal policies for this population.

The HSC Foundation roundtable was designed to bring together the aforementioned stakeholders to discuss the goals of, barriers to, and solutions for advancing health care transition.

Developmentally appropriate health self-management is the cornerstone for successful health care transition.

A core tenet of quality health care is patient-centered care, and person-centered planning is considered a hallmark of disability policy.

## Methodology

Dr. Santi KM Bhagat, Founder and President of Physician-Parent Caregivers, and Mr. Curtis Richards, Director of the Center for Workforce Development at the Institute for Educational Leadership, first reviewed current policies and the literature on health care transition and the topic of transition at large to develop the framework and following discussion topics for the roundtable:

- Meeting the health care needs of youth and young adults with chronic conditions and disabilities;
- Transformation of primary care in health care transition; and
- Improving the health care workforce for health care transition.

A core tenet of quality health care is patient-centered care, and person-centered planning is considered a hallmark of disability policy; both require involvement of patients/people at every level of the decision-making process. More often than not, patients/people are brought in too late in the process. PPC and IEL selected two young adults with chronic conditions and/or disabilities and a physician-parent to serve as discussion leaders at the roundtable: Ms. Jodie Neukirch, Dr. Amy Long, and Dr. W. Carl Cooley.

PPC and IEL then conducted an analysis of the patient and family, health care, professional development, and policy systems to identify stakeholders for the roundtable. Stakeholder representatives who were invited to participate included:

- Young adults with chronic conditions and disabilities;
- Parents;
- Physicians;
- Physician-parents;
- Foundations; and
- Federal officials who impact health care transition.

Finally, PPC and IEL developed a list of 55 national potential participants from the aforementioned stakeholder groups who could provide expertise on the set of objectives mentioned earlier. Envisioning an interactive roundtable, discussion leaders for each of the three topics mentioned above were identified and personally invited by email. All three accepted. Priority was placed on experts who exemplified young adult-centered philosophies. Invitations

were sent by email to all 55 potential participants, and 45 agreed to attend. Prior to the event, several policy papers that helped to inform the development of the roundtable were emailed to the participants in preparation for the discussion.

On July 24, 2012, 42 experts from across the country met at the National Youth Transitions Center in Washington D.C. to participate in a half-day roundtable to discuss the status, challenges, barriers, and solutions for advancing health care transition for young people with chronic conditions and disabilities. The participants were given the following supporting articles:

- *A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs* (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine);
- *Clinical Report—Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home* (Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians);
- *Health Care Transition for Young People with Chronic Conditions and Disabilities Policy Brief* (Physician-Parent Caregivers);
- *Health Issues Impacting Youth Transitions Roundtable* (The HSC Foundation);
- *Enhancing Health Care Transition for Youth and Young Adults Living with Chronic Medical Conditions and Disabilities: Suggestions for Reform* (Gleason, B.L.; Palmer, J.; Bhagat, S.K.M.; Reiss, J.);
- *Provision of Educationally Related Services for Children with Chronic Diseases and Disabling Conditions* (American Academy of Pediatrics);
- *Youth in transition: care, health and development* (Gorter, J.W.; Stewart D.; Woodbury-Smith M.);
- *Transition from Pediatric to Adult Care: Internists' Perspectives* (Peter, N.G.; Forke, C.M.; Ginsburg, K.R.; Schwarz, D.F.); and
- *Guideposts for Success* (National Collaborative on Workforce and Disability for Youth).

In addition, a sign language interpreter and a meeting transcriber were in attendance.

## Objectives

Physician-Parent Caregivers and the Institute for Educational Leadership developed the following set of objectives to guide the roundtable discussion:

- Identify ways to increase the visibility of youth and young adults with chronic conditions and disabilities and their need for health care transition;
- Identify mechanisms to break down medical, policy, and programmatic silos driven by age, condition, or disability for youth and young adults with chronic conditions and disabilities;
- Identify barriers to improving the coordination of health care policy related transitions at the federal, state, and local levels for youth and young adults with chronic conditions and disabilities;
- Identify innovative strategies and curricula needs for improving the health care workforce's ability to serve youth and young adults with chronic conditions and disabilities, including pediatric- and adult-centered primary care providers and specialists; and
- Develop a set of recommendations and an action agenda that can be implemented by the public and private sectors to advance health care transitions for youth and young adults with chronic conditions and disabilities.

## Key Findings

Ms. Jodie Neukirch and Dr. Amy Long kicked off the roundtable with a discussion on **Meeting the Needs of Young Adults with Chronic Conditions and Disabilities**.

### *Defining the Population*

**“The definition should be inclusive of the broader population of youth and young adults with chronic conditions and disabilities that require long-term, coordinated, patient-centered health care services, including community-based care and other services.”** Since youth and young adults are still in the process of growth and development, it may not be appropriate to base



inclusion solely on the federal definition of disability (i.e., ability to perform daily activities). Instead, it makes sense to include emerging signs and symptoms of physical, developmental, and behavioral risks, which may not manifest as activity-related limitations until later in life. After all, youth with chronic conditions and disabilities carry their health issues throughout the rest of their lifespan.

Many chronic conditions wax and wane, resulting in unpredictable cycles of high use of care that alternate with minimal to no need for care. Relying on health care utilization to define this population can lead to failure to include those who are in the period of minimal care use. Another limitation is that some young adults may not use the health care system at times when they need to. The definition should be based on the expected need of services over a lifetime. This approach would permit identification of the target population and the development of a system of care that would optimize their health care transition and health.

Defining this population is challenging, but a larger looming problem is the reluctance of young people to self-identify for fear of being labeled or stigmatized. Young people just want to fit in with their peers: they do not want to be perceived as different or needy. **“Many young adults with invisible disabilities or chronic conditions do not see themselves as disabled.”** Also, many youth with disabilities may not self-identify if they perceive their condition to be ‘normal’, as it is all they have ever known. Young people who do not self-identify get left out of programs and services targeted to them. Without access to guidance, they are likely to face problems with their health care, education, and employment.

### ***How We Can Help Young People with Chronic Conditions and Disabilities***

Youth and young adults need to be educated about the long-term nature of their conditions and the potential impact on their lives. **“Young people who are born with a condition or disability often have a better understanding of how to self-manage their health and lives compared to those who develop a condition later in childhood or adolescence.”** It often takes months to get young people ‘up to speed’ for a process that normally takes years.

**“Many young adults with invisible disabilities or chronic conditions do not see themselves as disabled.”**

“Adult providers need to provide the right environment and find the right words to make their practices an accepting, welcoming place for young adults.”

**“Adult providers need to provide the right environment and find the right words to make their practices an accepting, welcoming place for young adults.”** Young adults need to know and feel that the adult-centered health care system understands who they are and what they need, and that they will not be stigmatized. The move from pediatric- to adult-centered care is a major cultural shift; pediatricians nurture their patients and embrace family-centered care, whereas internists tend to be minimalistic. Like their peers, these young people are consumed with their transition to college/vocational school and work; new communities, friends and romance; living on their own without mom, dad and their siblings; and adult experiences. They do not have the energy, time, or knowledge to focus on transitioning from pediatric- to adult-centered health care. If the adult-centered system does not welcome them wholeheartedly, these young adults are at risk for falling out of sight.

While health care transition is often a crucial first step for youth with chronic conditions, it is equally important to ensure successful transitions in education, employment, self-management, and advocacy. Youth with chronic conditions and disabilities access multiple systems that do not collaborate or function well together. Transitioning to multiple siloed systems in young adulthood further compounds the confusion and makes it impossible for young adults to succeed in transition. **“These youth and young adults need an organizational approach to cross-system coordination, where one entity transcends the individual systems and works to minimize the confusion and complexities that families face.”**

### ***Policy and Programmatic Changes***

The importance of insurance reform for these young adults impacts the decisions they make about their education and careers. They may opt not to pursue higher education out of concern that students have difficulty securing adequate coverage, and they may choose a vocation depending on whether it will provide adequate health care insurance. **“The Patient Protection and Affordable Care Act addresses some of these issues by allowing young people to remain on their parent’s plans until age 26, but this is just a start as more reform is needed to ensure satisfactory coverage and access to quality health care.”**

In many programs, patients either qualify for all services or none at all. Typically, those who qualify are the most severely impaired, leaving out the bulk of the population that needs services. **“Decision-makers should end the approach of ‘all-or-none’ support and modify eligibility criteria and resource allocation to provide appropriate levels of support and services to all youth and young adults in need.”**

**“The glaring absence of data systems for the population of young adults with chronic conditions and disabilities continues to preclude any chance to advance progress for this population.”** In light of the lack of adequate data on health care transitions, undue emphasis is placed on anecdotal evidence. Some good data exists for individual illnesses, but, as noted earlier, health care transition cannot be addressed effectively through a condition-specific approach. Challenges exist both in defining desired outcomes and in evaluating those outcomes. Since most pediatric data systems end at age 18 and adult systems start at 18, data on transition may not exist or get lost since the two systems do not communicate.

**“Large-scale research should be conducted on young adults with chronic conditions and disabilities to identify what they want out of the health care system.”** It is important to understand the young adult perspective on what they feel when they continue to access care in the pediatric office or hospital. In order to develop policies, programs, and models of care that are patient-centered, young adults need to voice how they want to access care in the adult-care setting along with other young adults.

### ***Transforming Primary Care***

Dr. W. Carl Cooley led the discussion on **Transformation of Primary Care**. A champion of pediatric medical homes and health care transition, he reiterated that insufficient progress has been made over the past decade, in spite of two joint AAP/AAFP/ ACP publications that highlighted specific strategies and practices to improve health care transition. Implementation of these practices has been limited to a few specialties, such as cystic fibrosis, whereas, no evidence exists for uptake by primary care.

**“Large-scale research should be conducted on young adults with chronic conditions and disabilities to identify what they want out of the health care system.”**

“The goal is for every young person to have a written health care transition plan.”

The specialty-focused health care system is not equipped to accommodate the estimated one million young adults with chronic conditions and disabilities who transition to adulthood every year. **“The primary care system and multidisciplinary provider teams need to serve as the gateway for health care transition.”** The best models for producing high-quality coordinated care are based on multidisciplinary teams that understand the community system.

Dr. Cooley, co-director of Got Transition, a national health care transition center supported by the U.S. Department of Health & Human Services, Maternal & Child Health Bureau, shared his experiences on quality improvement methodologies to improve health care transition. Dr. Cooley steers pediatric- and adult-centered provider dyads to co-develop a health care transition system that includes tools such as patient registries and readiness assessments. Many of the necessary tools have been developed and are awaiting testing, refinement and dissemination.

The field of health care transition is still in an aspirational phase. Many challenges remain in spite of extensive efforts. **“The goal is for every young person to have a written health care transition plan.”** Some challenges include:

- Many pediatric practices have yet to implement the first step, i.e., creating written health care transition policies;
- Pediatric providers seldom prepare their patients for the adult-centered system. Young patients typically land up in the offices of adult-centered primary care physicians without the information that the new doctor needs to understand their history or health condition. Patients seldom have a fact sheet, medical summary, or care plan, and in many cases, the pediatrician has never spoken to the adult-centered doctor;
- Pediatric providers may not be pro-active about transition, because they do not believe their patients will have an adult-centered system to transition into. Even in these cases, they need to develop health care transition plans and teach the patient and family about self-management and advocacy, because patients can end up in the emergency room or community medical clinic, where they will need to know how to advocate and provide a medical history; and
- In the adult-centered system, primary care doctors tend to

focus on the larger population of patients with adult-onset conditions. **“Most adult-centered primary care practices fail to recognize young adults as a distinct population and health care transition as a critical process of care. A new young adult patient is treated the same way at the first visit as an elderly patient is treated at the 90<sup>th</sup> visit.”**

Many health organizations are just beginning to realize the value of including young adults with chronic conditions on their quality improvement teams (e.g., for medical homes and health care transition). However, it can prove difficult to find young adults to serve in this type of leadership role.

The 2011 joint clinical report by the AAP/AAFP/ACP highlights the need to empower the patient and family, a movement that remains in the early stages. Primary care providers can act as conduits for encouraging such empowerment.

### ***Policy and Programmatic Changes to Address the Challenges***

**“Pediatric- and adult-centered primary care providers will not invest in serving transitioning patients unless they receive adequate reimbursement for the extra time and commitment needed.”** Under the current system, pediatricians, however well intentioned, do not have the incentive or capacity to engage in a 1.5-2 hour session to develop a health care transition plan for a complex patient.

Employers, health plans, and other payers need to become aware and knowledgeable about the need for and impact of health care transition. “Payers need to amend their payment structures to support transition-related services.” These considerations include:

- Employers and plans could require health care transition plans for young people with chronic conditions and disabilities;
- Medicaid’s EPSDT (Early Periodic Screening, Diagnosis and Treatment) program could make health care transition plans part of the standard medical package; and
- EPSDT could create specific billing codes for services that are not yet in place, such as readiness assessments.

**“Most adult-centered primary care practices fail to recognize young adults as a distinct population and health care transition as a critical process of care.”**

Little evidence exists to support payment reform. Some condition-specific data exists, but data for the broader population of chronic conditions and disabilities is sparse, particularly for cost-effectiveness. **“A large body of evidence will help accelerate payment reform; a meta-analysis of existing research might be a good first step.”** Once the evidence is developed, it needs to be disseminated widely, as many key stakeholders (i.e., program officials at the Center for Medicare and Medicaid Services and the National Institutes of Health) are unaware of the magnitude of the problem and the potential benefits of addressing it.

Maintenance-of-certification (MOC) requirements represent a potential “hook” to get practicing physicians involved in health care transition, e.g., providers could earn credit by participating in quality improvement activities related to transition. A module for health care transition could be developed for professional board associations like the American Board of Pediatrics.

Health care transition could be required for external designation and participation in demonstration projects; i.e., the National Committee for Quality Assurance could require practices to develop health care transition plans to be designated as Patient-Centered Medical Homes (PCMH). CMS and private payers could require development of health care transition activities as a prerequisite for pay-for-performance and other demonstration projects, including PCMH and Accountable Care Organizations.

Patient advocacy groups should be leveraged to advocate for health care transition. Many young people go to these groups for support, many of which are large and have substantial financial resources. While these organizations often focus on a specific condition, they are capable of having a disproportionate influence on lawmakers.

### ***State of the Health Care Workforce***

Dr. Cynthia Peacock, Director of the Combined Internal Medicine-Pediatrics Program and the Transition Medicine Clinic at the Baylor College of Medicine, provided an overview on **Expanding and Training the Health Care Workforce**. Dr. Peacock’s prior experience as a nurse gives her insights on strategies that include allied healthcare professionals. Dr. Peacock oversees the only transition clinic that is currently housed in adult-centered primary care.



**Model of Care:**  
***Integrated Community-Based Health Care  
Transition Clinic in Adult-Centered Primary Care***

- Serves patients who need care coordination that is not available in the community.
- Serves as an integrated medical home.
  - Proactive Care Coordination
  - Medical summary sheet developed at the first visit
  - Proactive care plan that is continually updated by nurses and care coordinators working behind the scene
- Coordinates with other systems and programs that serve youth.
  - Supportive employment
  - Transportation
  - Individualized education
- Model for team-based training on health care transition and care for young adults with chronic conditions and disabilities.
  - Physicians, Fellows, Residents, and Medical Students
  - Nurses
  - Allied health professionals
  - Social workers

**“The national shortage of physicians trained in health care transition and the care for childhood-onset chronic conditions and disabilities puts young people at grave risk for delaying or foregoing care.”**

The United States faces a critical shortage of pediatric- and adult-centered primary care physicians, pediatric specialists, nurse practitioners and physician assistants to care for young people with chronic conditions and disabilities. Physicians who are trained in combined internal medicine-pediatrics are uniquely trained to work in the pediatric system and the adult-centered system. These physicians can accelerate progress in health care transition by providing care and training the health care workforce. However, with just 76 programs graduating 400 physicians a year, too few exist to take health care transition to the next level. Until federal or state incentives are created, academic centers will continue to exhibit a lack of interest in training primary care doctors.

Competing priorities  
and financial incentives  
prevent medical schools  
from proactively adding  
health care transition to  
their curricula.

**“Equally daunting is the lack of medical training on childhood-onset chronic conditions, disability care and competency, medical homes, and care coordination for current, and future physicians.”** The few who are trained lack the needed tools and resources.

### ***Policy and Programmatic Changes***

Maintenance-of-certification (MOC) adult providers may become more interested in this population if they could earn credit toward MOC or licensure requirements by attending conferences or completing educational or training programs.

Competing priorities and financial incentives prevent medical schools from proactively adding health care transition to their curricula. Accrediting bodies could foster rapid change by including health care transition training for accreditation.

Surveys of medical school deans show they believe their students receive disability training, but surveys of their students suggest otherwise. As medical school and residency program curricula shift from experiential to competency based training, demonstrating competency in care of young people with childhood-onset conditions and disabilities could be required.

Several medical schools are adopting innovative approaches to increase exposure to the plight and care of young people with chronic conditions and disabilities, but with inadequate funding and coordination, these programs can only operate as pilot projects. Some approaches include:

- Young adults or their families share stories on living with chronic conditions and/or disabilities;
- An accredited elective provides training in developmental medicine for fourth year medical students. Students planning to go into pediatrics take the adult version, while those planning to pursue adult care take the pediatric version; and
- A few family medicine residency programs focus on adults with intellectual and developmental disabilities.



**“Peer navigators or specialists can provide age-appropriate support by meeting with patients beforehand and accompanying them to medical appointments. Peer navigators assist with care coordination, outreach, needs and symptom assessment, and transportation.”** This model works in the mental health, cancer, and HIV fields, and could be applied to young people with chronic conditions and disabilities. The Federal Government funds technical assistance to support peer advocate training, and the mental health field certifies peer specialists. Health plans and organizations use this approach for behavioral health.

While hospitals and practices recognize the value of care coordination, they seldom have permanent dedicated staff. Providers will not fund positions that do not generate revenue. Public and private payers will have to agree to pay for care coordination to encourage providers to invest in dedicated care coordinators.

## Recommendations

The following recommendations emerged from the spirited and substantive discussion at the roundtable:

- Convene a series of similar, focused discussion groups to identify strategies to advance health care transition and the care for young adults with chronic conditions and disabilities. Five distinct roundtable discussion groups need to be convened that include: a) young adults with chronic conditions and disabilities; b) family members of young adults with chronic conditions and disabilities; c) disability and patient advocacy groups; d) health care professionals; and e) a cross-boundary group of government officials;
- Convene a national summit of multi-stakeholders to address issues of health care transitions for youth with chronic conditions and disabilities that builds upon the information gathered from the stakeholder group convenings;
- Conduct a set of focus groups to characterize self-management, advocacy, health status, health care needs, and quality of life outcomes of young adults with chronic conditions and disabilities, their siblings, and parents; and
- Create a mentoring program to help young people with chronic conditions and disabilities with self-advocacy.

“Peer navigators or specialists can provide age-appropriate support by meeting with patients beforehand and accompanying them to medical appointments.”

## Conclusion

A sense of urgency is needed if the rate of progress for young adults with chronic conditions and disabilities is to keep pace with their growth and development. Society, policy, and medicine must understand that the prevalence of this population is only increasing, and the longer their needs are ignored, the greater they will need medical care and public assistance. And, they are growing into adulthood and aging with their conditions.

The primary issues to be tackled include the following:

- Improve data collection systems for young adults with chronic conditions and disabilities;
- Promote payment reform for health care transition and care of childhood-onset of chronic conditions and disabilities;
- Expand the size of the health care workforce to care for these young adults; and
- Prepare and train the health care workforce to provide quality health care for these young adults as they age with their disabilities.

All young people have the right to dream, but until this population is made a national priority, their dreams will be thwarted by their continued struggle to access quality health care, self-manage their health, and manage medical bills. Like children, they need some guidance; like their peers, they can achieve their goals, given the right support and encouragement.

## References

- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*(6), 1304–1306. Retrieved from [http://pediatrics.aappublications.org/content/110/Supplement\\_3/1304.full](http://pediatrics.aappublications.org/content/110/Supplement_3/1304.full)
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Clinical report—supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*(1), 182–200. doi: 10.1542/peds.2011-0969
- American Academy of Pediatrics, Council on Children with Disabilities. (2007). Provision of educationally related services for children with chronic diseases and disabling conditions. *Pediatrics*, *119*(6), 1218–1223. doi: 10.1542/peds.2007-0885
- American Academy of Pediatrics, National Center for Medical Home Implementation. (n.d.). What is a Family-Centered Medical Home? Retrieved from <http://www.medicalhomeinfo.org>
- Callahan, S.T., Cooper, W.O. (2006). Access to health care for young adults with disabling chronic condition. *Arch Pediatr Adolesc Med*, *160*, 178–182.
- Collins, S.R., Robertson, R., Garber, T., Doty, M.M. (2012). Young, uninsured and in debt: Why young adults lack health insurance and how the affordable care act is helping. The Commonwealth Fund. Retrieved from [http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2012/Jun/1604\\_collins\\_young\\_uninsured\\_in\\_debt\\_v4.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2012/Jun/1604_collins_young_uninsured_in_debt_v4.pdf)

- Data Resource Center for Child and Adolescent Health. (2011). Maternal & Child Health Bureau core outcomes for CSHCN: Trending across years. *National Survey of Children with Special Health Care Needs*. Retrieved from [http://www.childhealthdata.org/docs/default-document-library/nschscn-trending-outcomes-synopsis\\_05-vs-09.pdf](http://www.childhealthdata.org/docs/default-document-library/nschscn-trending-outcomes-synopsis_05-vs-09.pdf)
- Gleason, B.L., Palmer, J., Bhagat, S.K.M., Reiss, J. (2009, October). Enhancing health care transition for youth and young adults living with chronic medical conditions and disabilities: Suggestions for reform. Retrieved from [http://www.physicianparent.org/siteimages/PPCpaper\\_web.pdf](http://www.physicianparent.org/siteimages/PPCpaper_web.pdf)
- Goodman, D.M., Hall, M., Levin, A., Watson, R.S., Williams, R.G., Shah, S.S., Slonim, A.D., (2011, June 27). Adults with chronic health conditions originating in childhood: Inpatient experience in children's hospitals. *Pediatrics*, 128(1), 5-13. doi: 10.1542/peds.2010-2037
- Gorter, J.W., Stewart, D., Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child: care, health and development*, 37(6), 757-763. doi: 10.1111/j.1365-2214.2011.01336.x
- Himmelstein, D.U., Thorne, D., Warren, E., Woolhandler, S. (2009). Medical bankruptcy in the United States, 2007: Results of a national study. *The American Journal of Medicine*, XX(X), 1-6. Retrieved from [http://www.pnhp.org/new\\_bankruptcy\\_study/Bankruptcy-2009.pdf](http://www.pnhp.org/new_bankruptcy_study/Bankruptcy-2009.pdf)
- Magrab, P.R., & Hillary, H.E.C. (Eds.). (1989). Proceedings from Surgeon General's Conference: *Growing up and getting medical care: Youth with special health care needs*. Washington, DC: Georgetown University Child Development Center. Retrieved from <http://permanent.access.gpo.gov/LPS107730/LPS107730/profiles.nlm.nih.gov/NN/B/C/Z/S/ /nbczs.pdf>
- Mangan, D., (2013, June 25). *Medical Bills Are the Biggest Cause of US Bankruptcies: Study*. Retrieved from <http://www.cnbc.com/id/100840148>

The National Alliance To Advance Adolescent Health. Got Transition?. Retrieved from <http://www.gottransition.org>

Okumura, M.J., Kerr, E.A., Cabana, M.D., Davis, M.M., Demoner, S., Heisler, M., (2009). Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*, 125(4), e748-e754. doi: 10.1542/peds.2008-3451

Patient Protection and Affordable Care Act of 2010, § 111-148 (2010). Retrieved from <http://www.healthcare.gov/law/full/index.html>

Perrin, J.M., Bloom, S.R., Gortmaker, S.L. (2007, June 27). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association*, 297(24), 2755-2759. doi:10.1001/jama.297.24.2755

Peter, N.G., Forke, C.M., Ginsburg, K.R., Schwarz, D.F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*, 123(2), 417-423. doi: 10.1542/peds.2008-0740

U.S. Department of Education, Office of Special Education Programs. Building the legacy: IDEA 2004. Available online at <http://idea.ed.gov>

U.S. Department of Health and Human Services, Health Resources and Services Administration, National Center for Workforce Analysis. Retrieved from <http://bhpr.hrsa.gov/health-workforce/index.html>

Wakschlag, S., Breslin, M., Yee, S. (Unpublished). The impact of the Affordable Care Act on transitioning youth with disabilities.

---

---

## **Roundtable Participants**

**Jackie Aitken**

Intern  
Physician-Parent Caregivers

**Kimberly C. Bates, MD**

Clinical Assistant Professor  
Ohio State University Internal Medicine & Pediatrics at Grandview

**Santi KM Bhagat, MD, MPH**

Founder and President  
Physician-Parent Caregivers

**Crystal R. Blyler, PHD**

Senior Researcher  
Mathematica Policy Research, Inc.

**Danielle T. Cameron, MPH**

Director of National Development  
National Health Foundation

**Thomas Chapman, MPH**

President and Executive Director  
The HSC Foundation

**Henry Claypool**

Senior Advisor for Disability Policy to the U.S. Department of  
Health & Human Services Secretary, and Principal Deputy  
Administrator of the Administration for Community Living  
U.S. Department of Health & Human Services

**W. Carl Cooley, MD, FAAP**

Chief Medical Officer  
Crotched Mountain Foundation,  
Medical Director  
Center for Medical Home Improvement,  
Co-director, Got Transition – National Health Care Transition  
Center & Adjunct Professor of Pediatrics, Dartmouth Medical  
School

**Judy Dickinson, BA**

Summer 2012 Intern  
American Association of People with Disabilities  
Center for Workforce Development  
Institute for Educational Leadership

**Ryan Easterly**

Manager, National Youth Transitions Initiative  
The HSC Foundation

**Alexander Enders, OTR/L, ATP**

Senior Research Associate  
Research and Training Center on Disability in Rural Communities  
University of Montana Rural Institute

**Sophia Jan, MD, MS**

Robert Wood Johnson Foundation  
Clinical Scholar  
University of Pennsylvania Health System, Division of General  
Internal Medicine  
Children's Hospital of Philadelphia, Division of General Pediatrics

**Jennifer Kemp**

Policy Advisor Team Lead  
Workforce System Policy  
Division of Policy Development  
Office of Disability Employment Policy  
U.S. Department of Labor

**Joy Lewis, LCSW, MPH**

Manager, Kaiser Permanente Outside Education and Health  
Policy Communication  
Kaiser Permanente International and Kaiser Permanente Institute  
for Health Policy  
Kaiser Foundation Health Plan, Inc.

**Sharon Lewis**

Administration on Intellectual and Developmental Disabilities  
Commissioner  
U.S. Department of Health & Human Services

**Paul H. Lipkin, M.D.**

Associate Professor of Pediatrics  
Director, Center for Development and Learning  
Kennedy Krieger Institute  
Johns Hopkins University School of Medicine

**Amy Long, MD**

Pediatric Resident  
Cincinnati Children's Hospital Medical Center

**Marie Mann, MD, MPH, FAAP**

Division of Services for Children with Special Health Care Needs  
Project Officer  
Maternal and Child Health Bureau  
Health Resources and Services Administration  
U.S. Department of Health and Human Services

**John Mathewson**

Executive Vice President, Strategy & Operations  
The HSC Foundation

**Margaret McManus, BA, MHS**

President  
The National Alliance to Advance Adolescent Health

**Cynthia Peacock MD, FAAP, FACP**

Combined Medicine-Pediatrics  
Program Director  
Internal Medicine Associate Program Director  
Transition Medicine Clinic Director  
Baylor College of Medicine

**Laura Pickler, MD, MPH**

Assistant Professor  
Family Medicine and Pediatrics  
University of Colorado  
Director Pediatric Oral Feeding Clinic, Special Care Clinic  
Children's Hospital Colorado

**Elizabeth K. Rasch, PT, PHD**

Staff Scientist and Chief,  
Epidemiology and Biostatistics Section  
National Institutes of Health,  
Mark O. Hatfield Clinical Research Center  
Rehabilitation Medicine Department

**Curtis Richards**

Director  
Center for Workforce Development  
Institute for Educational Leadership

**Harvey Schwartz, PHD**

Agency for Healthcare Research and Quality  
Office of Extramural Research, Education, and Priority  
Populations



**Jodie Senouillet, MS**

TALC Program Manager  
Hasbro Children's Hospital

**Jessica Stephens**

Policy Analyst  
Kaiser Commission on Medicaid and the Uninsured  
The Henry J. Kaiser Family Foundation

**Bonnie Strickland, Ph.D.**

Director, Division of Services for Children with Special Health  
Care Needs  
Health Resources and Services Administration  
Maternal and Child Health Bureau  
U.S. Department of Health and Human Services

**Robin Strongin**

President and CEO  
Amplify Public Affairs

**Paul Strumph, MD**

North American Regional Chief Medical Officer  
Vice President, Therapeutic Strategy Lead Cardiovascular/  
Metabolic  
Quintiles Transnational

**Patience H. White, MD, MA**

Vice President Public Health  
Arthritis Foundation  
Professor of Medicine and Pediatrics  
George Washington University School of Medicine and Health  
Sciences



Physician-Parent Caregivers, Inc. (PPC) believes that all children, young adults, and their families are entitled to Quality Health Care. Physicians who are parents of Young People with Chronic Conditions & Disabilities work with children, young adults, families, and physicians to find solutions for the delivery of optimal health care. PPC's mission is to empower all Children & Young Adults with Chronic Medical Conditions and Disabilities, and their families, to obtain Quality Health Care by building on the unique perspectives of Physician-Parents.



For a half-century, the Institute for Educational Leadership has championed the need for leaders at all levels to shake off their institutional constraints and work across boundaries to address the needs of young people and their families. Bound by no constituency, IEL serves as a catalyst that helps policy-makers, administrators, and practitioners at all levels to bridge bureaucratic silos and undo gridlock to improve outcomes for all young people and their families.



THE HSC HEALTH CARE SYSTEM

**The HSC Foundation**

The HSC Foundation provided generous support for the Roundtable and this report as part of its youth transition initiative.

The HSC Foundation is dedicated to improving access to services for individuals who face social and health care barriers due to disability, chronic illness, or other circumstances that present unique needs. The HSC Health Care System is a multi-faceted organization that weaves together a care coordination plan (Health Services for Children with Special Needs, Inc.), pediatric specialty hospital (The HSC Pediatric Center), and home health agency (HSC Home Care, LLC) with a parent organization, The HSC Foundation. Together, the System offers a comprehensive approach to caring, serving, and empowering individuals with disabilities.

[www.hscfoundation.org](http://www.hscfoundation.org)

Copyright © 2013 by The HSC Foundation