

## Transition's Missing Link: Health Care Transition

*"The two populations at greatest risk of medical neglect are the elderly and children. We will have to fight harder than ever for the funds to care for special needs children and young people.*

*It is unlikely that any administration or any Congress will address this issue on the clear merits of the situation -- in spite of the nation's affluence and prosperity. But the day will come when the business community will exert much greater pressure than at present for a more realistic method of funding health care. We must be prepared for that day so our special needs children are not shortchanged as the health care delivery system is rebuilt."*

- Surgeon General C. Everett Koop, M.D., 1989  
Surgeon General's Conference, Growing Up and  
Getting Medical Care: Youth with Special Health Care  
Needs.

In 1989, Surgeon General Koop had the foresight to bring experts together for a discussion and planning session to help youth with chronic conditions and disabilities transition to the adult health care system. Since this landmark effort, the American Academy of Pediatrics, American College of Physicians, and American Academy of Family Physicians developed a joint consensus statement on health care transition in 2002, and the Institute of Medicine's 2007 Future of Disability in America report made recommendations for health care transition. In spite of these calls to action, little progress has been realized over the past two decades.

The amount of care provided to adults with childhood-onset health conditions by pediatric providers and children's hospitals is stunning. Adults with childhood-onset conditions disproportionately use inpatient services in children's hospitals.

*NCWD/Youth's **Guideposts for Success** provide a framework for what all youth, including youth with chronic conditions and disabilities, need to make a successful transition to further education, careers and adulthood. One of the key elements of the **Guideposts** under **Connecting Activities** is health care. This Policy Brief draws on a number of recent health care-related reports to identify policy strategies for improving health care transition for youth with chronic conditions and disabilities.*

Transition age young adults, 18-21 years, comprise the fastest growing segment, followed by adults over 21 years and a significant percentage who are in their 30s and 40s (Goodman et al., 2011). While pediatric providers and hospitals may have unique expertise to manage childhood-onset conditions, they lack the knowledge, infrastructure, and ability to address compounding adult health issues and coordinate with adult care providers and organizations.

A growing number of families and health care providers continue to call for a system to provide health care transition and quality health care for young people with chronic conditions and disabilities. Until policymakers and health care providers develop and implement this system, the nation's most vulnerable young adults will continue to be at risk for depending on Medicaid and/or Medicare; they will be at risk for joining the ranks that depend on SSI and food stamps; and most importantly, they will be at risk of avoidable morbidity and mortality. Surgeon General Koop's warning was not heeded: children and young adults with chronic conditions and disabilities were not prioritized in the 2010 Patient Protection and Affordable Care Act (PPACA). These young people will continue sacrificing their dreams and lives until the health care system is able to meet their needs.

### Transition

Transition for youth with disabilities encompasses the move from high school to the world of adulthood. It is centered in the special education system and rooted in the Individualized Education Program. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) mandates transition planning to



start no later than the age of 16 years, and yet, many states still start as early as 14 years.

Typical transition planning includes post-secondary education or vocational training, adult education, employment, and independent living or community participation. This template works well for many youth, but it is inadequate for those who have chronic health conditions, e.g., cerebral palsy and Down syndrome, or invisible disabilities, e.g., epilepsy, depression, migraine, attention deficit hyperactivity disorder, Crohn's disease, chronic fatigue syndrome, congenital heart disease, diabetes, asthma, obesity, and HIV/AIDS. Categories for IEP eligibility that require chronic condition management are highlighted in Figure 1.

**Figure 1:  
Categories of Disability under IDEA**

Autism	Orthopedic impairment
Deaf-blindness	Other health impairment
Deafness	Specific learning disability
Emotional disturbance	Speech or language impairment
Hearing impairment	Traumatic brain injury
Intellectual disability	Visual impairment
Multiple disabilities	

Young adults with chronic health conditions first need to learn to manage their health and wellness if they are to succeed in any of the other life areas.

Transition planning for young people with chronic conditions includes the acquisition of knowledge and skills to navigate the health care system and manage their own health. The move from pediatric to adult health care is marked by health care transition. This process naturally originates in the health care system and needs to better connect with the interagency transition planning that starts in the education system.

### **A New Population: Young Adults with Chronic Conditions and Disabilities**

Every year, 750,000 young people with chronic conditions and disabilities enter adulthood and a health care system that is ill prepared to care for them (Scal & Ireland, 2005; Goodman et al., 2011). Many of these young people would not have survived in the past, but advances in medicine and technology allow them to grow up into young adults and beyond (Perrin, Bloom, & Gortmaker, 2007). However, health

policy and health care delivery for young adults have not kept pace (Gorter, Stewart, & Woodbury-Smith, 2011; Cooley & Sagerman, 2011).

A standard inclusive definition and age boundaries are lacking for this new population (Gleason, Palmer, Bhagat, & Reiss, 2009; Gorter, Stewart, & Woodbury-Smith, 2011). Acceptable terminology and age-related definitions are critical for planning and evaluation, data collection, research and policy. Current terminology includes language that may be confusing, i.e., special health care needs. The implied inclusion of chronic health conditions in the term 'youth with disabilities' can create confusion. While there is significant overlap, it is critical to recognize several distinctions:

1. Individuals with chronic health conditions may not consider themselves disabled, particularly those with invisible conditions;
2. Individuals with disabilities may not have chronic health conditions;
3. Young people with physical or intellectual disabilities tend to have similar manifestations from day-to-day, while those with chronic conditions have symptoms that are episodic, unpredictable, and wax and wane; and,
4. The special education statute does not adequately address chronic condition needs, e.g., excusal for absences and hospitalization, tutoring and technology to facilitate inclusion and achievement during and following absences.

Young people who have chronic health conditions require ongoing management of their health and wellness. Management of their health conditions is complex and necessitates managing medications, health status, insurance, medical appointments, hospital stays, and absences from school and work. During childhood, parents and pediatric medical providers assume responsibility for chronic care management. In adulthood, chronic care management is ideally transferred to the young adults and/or caregivers and adult medical providers. Young people who have physical or intellectual disabilities may not need chronic care management, but they need culturally sensitive health care, i.e., care tailored to their individual needs or care to prevent secondary conditions. In addition to chronic condition management and disability specific management, both groups need the same primary and preventative care that their peers need, e.g., immunizations, gynecological care, nutrition, and exercise counseling. For example, a young person



with asthma may need culturally-sensitive health care as well as supportive services to ensure that he/she lives in healthy housing conditions. Or, self-care for a young woman with diabetes will include learning to manage her health as well as learning how to manage her diet and exercise routine.

Research shows that regardless of the condition or disability, young people need similar supports and confront common barriers in their transition to adult health care (Gorter, Stewart, & Woodbury-Smith, 2011). Practice guidelines for health care transition recognize that all young people require a common template of care and there are a couple of individual planning tools in development (Cooley & Sagerman, 2011). These factors underscore the need to address transition from a population-based approach and the need to articulate the unique aspects of the chronic health condition and disability groups.

## Data & Health Surveillance

While America collects national and state data on children and adolescents with special health care needs, limited data exists on young adults 18 years and older. Consequently, no one has a real picture of young adults with chronic conditions and disabilities. Childhood data shows dramatic increases in the prevalence of special health care needs with age, almost doubling from 9.3 percent for newborn to 5 years to 17.7 percent for 6-11 year olds (Data Resource Center for Child and Adolescent Health, 2012). The trend continues to increase for 12-17 year olds to 18.4 percent, so it is important what happens in young adulthood. Data from the 2009-2010 National Survey of Children with Special Health Care, obtained from the Data Resource Center for Child and Adolescent Health Needs, is shown in Table 1.

**Table 1:  
Prevalence of Children and Young Adults with  
Special Health Care Needs**

Age Range (years)	Percentage (%)	Estimated Prevalence
0-5	9.3	2,328,780
6-11	17.7	4,292,886
12-17	18.4	4,581,950
18-29	Data not available	Data not available

Source: Data Resource Center for Child and Adolescent Health, 2012

Conservative extrapolations, i.e., using the prevalence from the 12-17 year old age group in this national study, suggests an estimated 9.53 million American young adults, aged 18-29 years, live with chronic conditions and/or disabilities (Derived from the 2009-2010 National Survey for Children with Special Health Care Needs and 2010 U.S. Census data).

In addition to information on the incidence and prevalence of chronic conditions and disabilities in young adulthood, there is a void of information on their health status and health care. Critical health surveillance measures that would provide a snapshot include the following: insurance coverage; access to care and services; health status and impact on education; work, independent living and participation; and financial impact and status. Young people are known to delay or forego care because of cost, and they struggle to find adult providers who know how to manage their childhood-onset conditions (Callahan & Cooper, 2006). One major concern is the extent to which young adults with chronic conditions seek unnecessary care in emergency rooms, care that is best provided by primary care physicians or specialists. Avoidable emergency room care is suboptimal, expensive and further burdens an ailing health care system. Young people who lack a usual source of care are at extreme risk of suffering from health deterioration and developing secondary mental or physical health conditions (Gorter, Stewart, & Woodbury-Smith, 2011).

## Health Care Coverage

The Patient Protection and Affordable Care Act (PPACA) immediately increased access to insurance for younger young adults by allowing them to stay on their parents' plan until age 26. While this was an important step forward, it neglects to address health care coverage for older young adults. All parents may not have private insurance coverage, and among those that do, some may not be able to afford to cover their young adult children who age out of Medicaid (Wakschlag, Breslin, & Yee). For young adults whose parents cannot cover them, those with chronic conditions and disabilities continue to be particularly vulnerable for the following reasons:

- (1) In college, they may not qualify for school-based health insurance because of difficulty in maintaining full-time status because of their medical issues;
- (2) They have difficulty obtaining employment-based insurance coverage because they



cannot obtain full-time employment in mid- to large-size companies; and,

- (3) About 74 percent who met childhood Medicaid's eligibility criteria fail to meet SSI disability criteria, which is necessary for adult Medicaid eligibility. Thus, they are forced into low-income jobs or unemployment to qualify for and maintain SSI eligibility (Gleason, Palmer, Bhagat, & Reiss, 2009; Wakschlag, Breslin, & Yee).

## **Guaranteed Coverage Does Not Guarantee Access**

While PPACA guarantees access to insurance for some young adults, it does not guarantee access to health care. The first barrier young adults with chronic conditions and disabilities face in the adult health care system is the struggle to find adult doctors who know how to care for their childhood-onset conditions and disabilities (Okumara et al., 2009). The health care system was taken by surprise when children with chronic conditions and disabilities started living into adulthood; physicians were not taught to provide ongoing care for this population as they age into adult-centered health care. As a result, young adults and adults often continue to seek health care from their pediatric providers (Gleason, Palmer, Bhagat, & Reiss, 2009).

Young people who transition to adult Medicaid lose access to aspects of their care previously deemed necessary to enable quality of life:

- Young adults who qualify for adult Medicaid lose the protective benefits of childhood Medicaid's Early and Periodic Diagnostic, Screening and Treatment (EPSDT) program for comprehensive chronic condition care and management.
- Adult Medicaid may limit the extent of services, use narrower definitions for medical necessity, and deem certain services covered in childhood as optional.
- Medicaid pays for services that enable young people with significant disabilities to live in the community, but it favors paying for institutionalization. Waiting lists in 38 states for community-based services can force young adults to wait more than two and half years; some of these young people are forced to move into institutions because they no longer receive the personal services they had as children to maintain basic function, e.g., to

eat, dress, bathe, etc. (Wakschlag, Breslin, & Yee).

## **Health Care Transition**

Health care transition actualizes the move from pediatric-oriented to adult-oriented health care and the mastery of developmentally appropriate self- or shared-health management (Cooley & Sagerman, 2011). It is not a simple transfer of care, it is a multi-year process that envelopes and integrates the young person along with his/her family, the pediatric team, and the adult-centered medical team (Peter, Forke, Ginsburg, & Schwarz, 2009). This process is ideally implemented by age 12 and completed between the ages of 18 and 21 (Cooley & Sagerman, 2011). According to the 2002 Joint Consensus Statement by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, "The goal (of transition) is 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...Optimal health care is achieved when every person at every age receives health care that is medically and developmentally appropriate."

In 2011, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians issued a joint clinical report with practice guidelines for health care transition (Cooley & Sagerman, 2011). This report includes a template for all young people with a carve-out for those who require chronic condition management. Health care transition must be developed and implemented according to individual needs. The goals and process will vary based on disability, chronic condition, intellectual and developmental capacity, maturity, and family support.

## **Medical Homes**

Health care transition practice guidelines describe the pediatric medical home as the starting point, where the pediatrician works with the young person and his/her family until care is firmly established in an adult medical home (Cooley & Sagerman, 2011). In the pediatric medical home, the pediatric primary care team works with the child and family to provide accessible, continuous, comprehensive, coordinated, compassionate and culturally effective care to meet the family's medical and non-medical needs (National



Center for Medical Home Implementation, n.d.).

Medical homes are particularly critical for children with chronic conditions and disabilities, as evidenced by the *Healthy People 2010* objective for 100 percent of children with special health care needs to have access to a medical home (Centers for Disease Control and Prevention, 2010). However, only 43 percent of children with special health care needs had access to a medical home in 2009-2010 (Data Resource Center for Child and Adolescent Health, 2012).

According to the National Survey of Children with Special Health Care Needs, youth who receive care in a pediatric medical home are twice as likely to receive transition services (Data Resource Center for Child and Adolescent Health, 2012). Health care transition is one of the six critical indicators that the U.S. Department of Health and Human Services' Health Resources and Services Administration uses to measure the quality of a system of care for children with special health care needs (U.S. Department of Health and Human Services, 2008). However, a 2005 study showed that just 16.4 percent of parents of youth with special health care needs had discussions with their providers about changing health needs and the shift to adult providers, and had developed a plan for transition (Scal & Ireland, 2005).

### Doctors for Young Adults?

Moving from the pediatric to the adult health care system requires well-prepared physicians in both spheres. Pediatricians have been driving the transition movement forward, only to find a paucity of receptive adult-oriented physicians, both in primary and specialty care (Peter, Forke, Ginsburg, & Schwarz, 2009). Adult physicians lack training in childhood-onset and congenital disorders, and they face barriers in meeting young adults' psychosocial needs (Peter, Forke, Ginsburg, & Schwarz, 2009). Physicians say systemic barriers at the policy and practice levels prevent appropriate treatment of young adults with chronic conditions, citing inadequate reimbursement and poor mental health support for young adults (Okumara et al., 2009).

The move from pediatric to adult health care also includes preparing the young person to take developmentally appropriate responsibility for his/her health and health care (Cooley & Sagerman, 2011). Pediatricians and adult providers must work with both the parents and youth/young adults. Understanding

the role that parents play in transition starts with recognizing that they may have critical information that their children may not provide (Gorter, Stewart, & Woodbury-Smith, 2011; Peter, Forke, Ginsburg, & Schwarz, 2009).

### Improved Quality of Life

The ultimate outcome of health care transition is improved quality of life for young adults. Young adults with chronic conditions and disabilities who have an adult medical home and are able to take care of their own health and health care are more likely to be able to pursue opportunities related to education, employment, and independent living and participate more fully in the community.

Current information about the economic status of young adults with chronic conditions and disabilities is lacking because of the lack of data and health surveillance. The little information that is available is dismal. They are three times more likely than their peers to live in poverty (White & Hackett, 2007), and young adults with disabilities spend 6 percent of their annual income, more than twice that of their non-disabled peers, on out-of-pocket health care costs (Wakschlag, Breslin, & Yee).

All young adults are at a critical juncture: getting them on the right track in education and employment is critical to ensuring long term success in health care decision making and management, and ultimately, financial independence. This rings even stronger for young adults who have chronic conditions and disabilities.

### Emerging Policy Agenda

Health care transition is a mandatory first step in transition for young people with chronic conditions. Health care transition is complex; it is an element in the health care system and in the process of transition. Interrelationships first need to be forged between young people, their families, pediatric providers and adult providers in the health care system. This health network then needs to blend with educational providers, transition service providers, vocational and training programs, transportation, housing and other community programs and services. Processes will need to be developed for health care transition and then merged with other processes for transition, including those for individualized planning and service tools.



Transition experts tend to focus on improving one component of health care transition, e.g., transition clinics, provider perspectives, or education. Innovative thought leaders view health care transition as a complex system, the functioning of which depends on components and their interrelationships (Hamdani, Jetha, & Norman, 2011). Some of these components can include people, organizations, and actions. A health care transition system includes stakeholders, services, and transition interventions. Systems thinking emphasizes the interrelationships and the impact they have on systems behavior. This approach helps leaders identify intervention strategies that will improve the system as a whole. Two critical leverage points to advance health care transition are:

1. Developing and promoting policies to improve resource allocation and services at the organizational level, and inter-organizational coordination and communication; and,
2. Training of health care professionals to facilitate health care transition and provide quality health care for youth and young adults with chronic conditions and disabilities.

The following seven-step strategy for improving health care policy is based on these two policy interventions, and is adapted from a policy paper published by the Physician-Parent Caregivers (Gleason, Palmer, Bhagat, & Reiss, 2009). The first three steps in the following plan bring stakeholders, particularly young people and their families, clinicians, and policymakers, together to develop and promote policies to improve resource allocation and services. The fourth, data collection and health surveillance, will inform the needs base and confirm whether the resources and services are enabling successful health care transition and health care related quality of life. And, focused professional development in the health care workforce, both physicians and allied providers, can improve health care transition outcomes. Health care reform and implementation of the PPACA provide an opportunity to advance key health care transition policy issues. Finally, the federal government in the United States plays a key role in providing oversight for young adults with chronic conditions and disabilities and their health care.

**1) Information Gathering:** Recommendations call for a series of stakeholder convenings to gather information about perceptions, attitudes, and the knowledge base on youth and young adults with chronic conditions and disabilities, health care

transition, and quality of life outcomes. The input of policy leaders, payers, health care providers, health centers and hospitals, medical education leadership, families, and young people is necessary not only to understand the status quo, but also to identify the needs and to develop solutions to improve resources and services for young people with chronic conditions and disabilities and their successful transition to adult health care (Peter, Forke, Ginsburg, & Schwarz, 2009). Person-centered care calls for young people and their families to contribute to the knowledge base to design programs that have appropriate resources and health care personnel, e.g., transition coordinators or coaches.

**2) Public Awareness and Education:** Health care transition and quality of life for young adults with chronic conditions and disabilities are 21<sup>st</sup> Century emerging global policy and health care concerns (Gorter, Stewart, & Woodbury-Smith, 2011). To realize progress in health care transition and care for young adults, it is critical to involve all the stakeholders at the outset.

Youth, young adults, and families must be educated about the need to complete the process of health care transition. Pediatricians, the most likely to be knowledgeable about this process, are still not familiar with the 2002 Health Care Transition Consensus Statement (Cooley & Sagerman, 2011). The medical community and insurance industry need to be educated, so they can develop appropriate delivery models supported by adequate reimbursement. Policymakers and policy influencers have to understand the need to create policies to support health care transition, health care workforce development, and data collection and health surveillance. Awareness and education are needed at the education, interagency, and community level to help young adults with employment, housing, transportation, and community participation (Gorter, Stewart, & Woodbury-Smith, 2011). Colleges, vocational training institutes, and the business community need to know that young people with chronic conditions and disabilities can and want to learn and work, and that successful health care transition minimizes absences and increases productivity.

**3) Community Building to Achieve Consensus:** Community building is another key step to advance health care transition policy. The first step is to bring young adults with chronic conditions and disabilities together so they understand they belong to a group



beyond their specific condition, and to educate them about health care transition and self-health management.

Patient-centered health care includes involving patients at every level of the decision making process. Young people want to be involved in the design and delivery of their health care services (Gorter, Stewart, & Woodbury-Smith, 2011). These two aims can be met by ensuring that young adults comprise the majority of the group charged with making decisions. Young adults who have experiential knowledge can serve as mentors or facilitators (Gorter, Stewart, & Woodbury-Smith, 2011). Having young adults spearhead the public awareness and education efforts puts a personal face on the issue and fosters peer engagement. Policymakers and health care providers will benefit from being able to query this group to ensure appropriate person-centered policies and practices are developed.

**4) Data Collection & Health Surveillance:** Data collection is a mandatory first step in any public health priority. The void of information about young people with chronic conditions and disabilities makes it impossible to make the health care, business, and financial case for them. At the very least, the following information needs to be collected:

- Incidence and prevalence by various demographic information, e.g. age, gender, ethnicity, socioeconomic status, geographic distribution, etc.;
- Development of new primary and/or secondary conditions, e.g. bipolar disorder, depression, multiple sclerosis, etc.;
- Access to health care providers, primary and secondary, clinics and hospitals, etc.;
- Details about health care, e.g. preventive care, chronic care management, care coordination, etc.;
- State of health and wellness, e.g. weight, diet, eating disorders, exercise routines, etc.;
- Type of health care coverage and financing, e.g. public, private, HMO, PPO, etc.;
- Quality of life beyond and/or impacted by health, e.g. education, employment, family, community participation, independent living, socialization, etc.;
- Individual and family support and impact; and,
- State of progress, success and approach with health care transition, e.g. self-directed, shared management.

This information can be collected publicly, privately, or through a joint public-private effort. Data and health surveillance information are key to ensuring successful health outcomes for young adults with chronic conditions and disabilities.

HHS' National Center for Workforce Analysis could collect information on the availability of trained pediatricians and adult care physicians who are caring for young people with chronic conditions and disabilities as they transition to adulthood.

**5) Health Care Professional Development:** The second critical policy intervention is stimulating the development of physicians and allied providers to care for young people and help them prepare, proceed through, and succeed in health care transition. Experts from various medical specialties, residency training program directors, academic and community physicians, medical societies, and federal and state government officials can convene to develop an agenda for developing the health care workforce. Young people and families can participate in discussions that center on identifying their needs and what kind of health professionals best fill particular roles.

Efforts to advance health care transition and train providers are underway in the pediatric community, but mostly in academic settings and for specific conditions. These programs are small and funded by small grants; they need to be studied en masse to glean information that can be spread to larger populations.

The Maternal and Child Health Bureau's Division of Children with Special Health Care Needs funded a three-year project to develop the National Health Care Transition Center, Got Transition. Got Transition piloted three training programs for pediatric and adult care physicians based on the National Initiative for Children's Healthcare Quality (NICHQ) breakthrough learning collaborative model. This is an example of training models that could be supported and replicated in the community.

The Bureau of Primary Care in Health and Human Services could help train pediatric and adult care physicians and allied health care providers about health care transition through its grants programs.

**6) Health Care Reform:** Many of PPACA's provisions target priority populations. It is critical to include young adults with chronic conditions and



disabilities and fund projects for this population. PPACA provides several opportunities to advance health care for young adults with chronic conditions and disabilities, in addition to insurance reforms. Some of these opportunities include the following:

- Improving and expanding the primary care workforce to support health care transition. In addition to the pediatric, family practice, and internal medicine workforce, the dually trained internal medicine/pediatrics workforce could be expanded. With their unique knowledge of both the pediatric and adult health care systems and cultures, internal medicine/pediatrics physicians are poised to promote health care transition. However, this group is currently too small in numbers to carry out health care transition for young people.
- The medical workforce needs to be educated about health care transition. This includes pediatric and adult primary care providers and specialists. Internal medicine/pediatrics physicians are particularly suited to develop a health care transition curriculum and implement training, both for physicians in training and in practice.
- Data collection could target young people with chronic conditions and disabilities, e.g., in community health centers, high-risk pools, insurance exchanges, Medicaid.
- Children and adults with childhood-onset chronic conditions and disabilities need to receive care in medical homes. Health care transition for young people should be a mandatory component and a clear health care quality indicator.
- Comparative effectiveness research needs to be conducted on health care transition and care of adults with childhood-onset chronic conditions and disabilities.

Expert working groups should explore potential opportunities immediately.

**7) Federal Oversight:** Health care reform and the federal government's health agencies (e.g., the Centers for Disease Control and the Centers for Medicare & Medicaid Services) place a large emphasis on mitigating, treating, and rehabilitating adults and the aging population. New initiatives include multiple chronic conditions and prevention of chronic conditions. It is important to recognize that many conditions originate in childhood and lead to

the development of secondary physical and mental health conditions, especially when quality health care is not provided, that continue throughout the lifespan. People with childhood-onset chronic conditions and disabilities comprise a discreet population that is medically underserved throughout their lifespan, and thus, is a group that experiences serious health disparities. Current shortages of primary care pediatricians and pediatric specialists are expected to worsen in the near future. At the same time, the projected shortage of adult primary care physicians will hamper the ability to develop and train a health care workforce that will be able to care for young adults with chronic conditions and disabilities.

The National Institutes of Health have several programs that focus on individual conditions, e.g., autism, diabetes, Fragile X, HIV/AIDS, and muscular dystrophy. Research on the broader population of young people with chronic conditions and disabilities with an emphasis on growth and development and quality of life outcomes in the young adult years would serve to improve the health and lives of millions of young people and their families.

A major obstacle in developing and implementing a policy agenda for young adults with chronic conditions and disabilities is that they do not have a home in any federal agency or department, especially inside the U.S. Department of Health & Human Services. The HHS Maternal and Child Health Bureau's Division of Children (MCHB) with Special Health Care Needs has programmatic authority to fund state Title V agencies for indirect and direct services for children and youth, but only up to age 18. This agency has promoted health care transition and adopted the lifespan approach, but it remains to be seen if the agency is authorized to oversee health care policy for young people beyond age 18. One approach is to increase MCHB's authority for young adults up to age 30. Another option is to create a new entity to oversee people with childhood-onset chronic conditions and disabilities through the lifespan, with an initial focus on the young adult segment. Wherever the lead agency is housed for young adults with chronic conditions and disabilities, its success will depend on how well it interfaces with the other relevant federal agencies inside of HHS (e.g., CMS, NIH, AHRQ) and across the federal government (e.g. Education, Labor, Social Security).





## Conclusion

A rising global concern in the 21<sup>st</sup> Century is the fate of young people who are outliving childhood-onset chronic conditions and disabilities and are attempting to lead productive lives well into adulthood. This population continues to be caught between the education and health care systems.

- The interagency process that takes place in the education system transitions many young people with disabilities. However, those with chronic health conditions have unique needs that are not met with current educational and transition policies and practices.
- The health care system does not address the needs of young people transitioning from pediatric to adult-oriented care very well. The medical community needs education on health care transition and quality health care, so young people with childhood-onset chronic conditions and disabilities can thrive, learn, work, earn, and participate in community life.

Simultaneous reforms in both systems that also integrate health care transition with educational-based transition are critical for successful outcomes.

Quality health care is based on patient-centeredness while disability policy calls for person-centered planning. Placing young adults front and center in designing a national agenda will bring them out of the shadows and allow them to pursue their ambitions and dreams of living healthy productive lives.

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The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) is composed of partners with expertise in disability, education, employment, and workforce development issues. NCWD/Youth is housed at the Institute for Educational Leadership in Washington, DC. The Collaborative is charged with assisting state and local workforce development systems to integrate youth with disabilities into their service strategies. This Policy Brief was written by Santi K.M. Bhagat, MD, MPH, President and Founder of Physician-Parent Caregivers, Inc., and Curtis Richards. To obtain this publication in an alternate format please contact the Collaborative at 877-871-0744 toll free or email [contact@ncwd-youth.info](mailto:contact@ncwd-youth.info). This Information Brief is part of a series of publications and newsletters prepared by the NCWD/Youth. All publications will be posted on the NCWD/Youth website at [www.ncwd-youth.info](http://www.ncwd-youth.info). Please visit our site to sign up to be notified of future publications. This document was developed by the National Collaborative on Workforce and Disability for Youth, funded by a grant/contract/cooperative agreement from the U.S. Department of Labor, Office of Disability Employment Policy (Number #OD-16519-07-75-4-11). The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Labor. Nor does mention of trade names, commercial products, or organizations imply the endorsement by the U.S. Department of Labor. Individuals may produce any part of this document. Please credit the source and support of federal funds.

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