



Healthy Transitions: A Pathway to Employment for Youth with Chronic Health Conditions and Other Disabilities

Policy Brief



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Introduction

“Health is an input into the production of human capital, the development of the competencies and knowledge that increase one’s ability to work and to be productive.” –Children with Disabilities. *The Future of Children*. Vol 22 No 1 Spring 2012. Ibid

All youth need to be connected to programs, services, activities, and supports that prepare them for meaningful post-secondary school options, enhance their ability to manage their physical, mental, and emotional well-being, and develop life-readiness skills to make informed choices. This is especially true for youth with disabilities, including those with chronic health conditions.

The U.S. Department of Labor’s Office of Disability Employment Policy (ODEP) frames its youth-policy work around the *Guideposts for Success (Guideposts)*, a series of principles articulating what all youth, including those with disabilities, need to transition successfully into adulthood. One key element of the *Guideposts is Connecting Activities*, which emphasize access to programs, services, and activities that help youth prepare to self-manage their health care needs, pursue meaningful careers, and make informed choices in their lives.¹ The *Guideposts* also state that youth, with and without disabilities, need development and leadership opportunities so they can meet the challenges of adolescence and adulthood through a coordinated, progressive series of activities and experiences. During the youth development process, youth learn about the interdependence between work and health and how to balance them optimally.

According to the U.S. Census Bureau, approximately 56.7 million (1 in 5) individuals of all ages, races, ethnicities, socioeconomic status, and educational attainment in the United States live with at least one disability.² Included within this population are people with high-prevalence chronic health conditions such as diabetes, asthma, chronic pulmonary disease, and obesity; less-common disorders historically considered “childhood conditions” such as cerebral palsy, cystic fibrosis, epilepsy, sickle cell anemia, and spina bifida; and other chronic conditions such as HIV/AIDS. Every year at least 500,000 to 750,000 young people with special health care issues become adults.³ Many of these youth have multiple conditions.⁴

The employment rate for youth with disabilities is historically below the national average for youth and

young adults of similar ages without disabilities. Up to 2 years after leaving high school, about 4 in 10 youth with disabilities are employed as compared to 6 in 10 same-age, out-of-school youth in the general population.⁵

Because the ability to manage one’s health is critical to going to school, learning, and transitioning into employment, ODEP commissioned a study on health care transition. The purpose of this 2012 study was to better understand the relationship between disability (including chronic health conditions); health and wellness; and transition and employment outcomes for youth with disabilities. In addition, the study examined the role health care providers play in establishing employment expectations. What follows are highlights from that research study.

Study Methods

The research process included interviews with key stakeholders. In addition, an extensive literature review was conducted across a number of systems and professional fields including:

- Health care professionals for models and procedures associated with transitions from pediatric to adult care;
- State education systems for policies and procedures associated with transition planning for students who receive special education and vocational rehabilitation services;
- Case managers for procedures and practices associated with transition planning for youth with disabilities and chronic health conditions;
- Workforce Investment Act program policies associated with youth with disabilities; and
- Federal and state legislation associated with health care, education, social security, and employment opportunities for people with disabilities.

Why does it matter? – The interdependence of health and wellness, and employment

The transition from youth to adulthood, school to work, and pediatric to adult medical care is filled with

developmental milestones for all youth, including those with chronic health conditions and other disabilities. Learning about the interdependence between health and wellness, and the transition to work is significant for three reasons. First, the transition to work and transition from pediatric to adult medical care intersect through health insurance because the prevailing model of health insurance in the United States is employer-based. According to recent estimates, 58.7 percent of people in the United States under age 65 were covered by employment-based health plans. This included 68.6 percent of working adults, 35.3 percent of non-working adults, and 54.8 percent of children. Of those not receiving employment-based coverage, 8.1 percent purchased health insurance directly from insurers and 11.7 percent received coverage through public programs.⁶ In an interview with the study team, Dr. Amy Long, Resident Physician at Cincinnati Children’s Hospital, described the relationship:

“Health insurance plays a huge role in employment transition. A youth could be interested in going to college, but may need to have a job in order to pay for it. If they get a job, they are at risk of losing their Medicaid coverage. Insurance is a huge problem.”

Before the passage of the Patient Protection and Affordable Care Act (ACA) in March 2010, young people frequently lost health insurance under their parents’ plans and in programs like Medicaid and Children’s Health Insurance Program when they reached the age 19 or when they graduated from high school or college. The ACA expands access to private insurance for young adults up to age 26 on a parent’s or family’s policy. In addition, beginning in 2014, it will also offer subsidized coverage through health insurance exchanges and expand Medicaid eligibility to all adults under age 65 with incomes up to 133 percent of the Federal Poverty Level (FPL).

Second, unmet health care needs can jeopardize employment and other aspects of the lives of youth with disabilities in ways that youth without disabilities may not experience. Therefore, continuous access to health services is vital for youth with disabilities as they transition to adulthood and enter the workforce. In addition to financial benefits (including access to employer-based health insurance), social connections, and increased self-esteem and productivity associated with working, work contributes to one’s overall health by helping them feel better about themselves and their prospects, and helps them maintain physical and mental

fitness.⁷ These positive consequences of work reinforce the importance of promoting a purposeful, planned health care transition model that engages youth with disabilities in managing their own health conditions and career exploration opportunities.

Lastly, disability is both a fundamental cause and consequence of poverty. Research conducted by the Center for Economic and Policy Research found that the income-poverty rate for people with disabilities is between two to three times the rate for people without disabilities.⁸

Transition Planning

What is health care transition planning?

According to the Society for Adolescent Medicine, health care transition is the purposeful, planned movement of adolescents and young adults with chronic conditions from child-centered to adult-centered medical care. Some researchers propose that the transition should begin on the day of diagnosis. The family must be involved in the decision process, but as the youth moves toward adulthood, both providers and parents should support the youth in leading their individualized health care transition planning process. The main components of health care transition planning include:⁹

- Transfer of care from pediatricians/pediatric nurse practitioners/ pediatric specialty physicians to adult specialty and primary care physicians and mid-level providers.
- Access to continuous and uninterrupted health insurance coverage for primary and specialty care needs when pediatric coverage terminates.
- The acquisition by the youth of knowledge and skills necessary to manage his or her daily treatment regimen independently.
- The ability to identify and advocate for accommodations needed to function more effectively in the work or school environment.
- Referral to transition and adult community agencies and resources based on individual needs for services.

Youth with disabilities, including those with chronic health conditions, have unique relationships with their health care providers. As one parent interviewed by the study team remarked, **“You change schools and programs, but you usually don’t change your pediatrician.”** In addition, health care professionals are frequently the first point of contact for families of youth with disabilities and chronic health conditions when completing required forms for programs and services.

Health care professionals, families, and other caring adults can leverage the health care transition planning process to reinforce high expectations and help youth learn how to manage their health care, become aware of their abilities, and prepare for future careers. Today, however, many youth with chronic health conditions and other disabilities have no experience managing their own health care, making appointments, or even discussing the specifics of their condition. As cancer advocate Andrew Herleman explained, **“All of this planning gives the patient something to focus on besides their treatment.”**¹⁰ In addition, youth who learn to manage their health-care are simultaneously developing transitional skills such as problem solving, self-advocacy, informed decision-making, and communication that can enhance their job readiness and career development and exploration.

The Role of Health Care Providers – The Vision

Health care transition planning for youth with disabilities, including those with chronic conditions, came to the forefront in 1989 when former Surgeon General Dr. C. Everett Koop convened a conference of family members and health professionals to focus on the health needs of youth as they transition from school to work and from home to independent living. In his introductory remarks, Dr. Koop underscored the importance of health care transition in the overall transition to adulthood:

“Before I leave my position, I would like to recall one major issue ...which has not been adequately addressed and which is a significant barrier to our adolescent and young adult population as they pursue independence. I refer to the obstacles they encounter and must surmount if the provision and quality of medical care is to continue from childhood through transition to adulthood.”¹¹



Dr. Koop challenged conference attendees to, “...clearly identify the problems and plan concrete efforts which each of you can pursue within your own organization. Let us then outline some efforts we can jointly pursue to knock down the barriers currently preventing our young people from living their lives to the fullest.”¹²

The Society for Adolescent Medicine answered the call in 1993 by defining transition as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care.”¹³

In 1999, the Institute for Child Health Policy hosted the conference, *“Transition: You Can Make it Happen in Health Care,”* as follow-up to the Surgeon General’s 1989 conference. This conference framed the health care transition component of the U.S. Department of Health and Human Services’ Maternal and Child Health Bureau’s (MCHB’s) *Healthy and Ready to Work Initiative*, establishing as its overarching goal that, “All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.”¹⁴ Today, MCHB is still instrumental in promoting the importance of seamless, effective, and comprehensive services for all youth and families during this major life transition.¹⁵

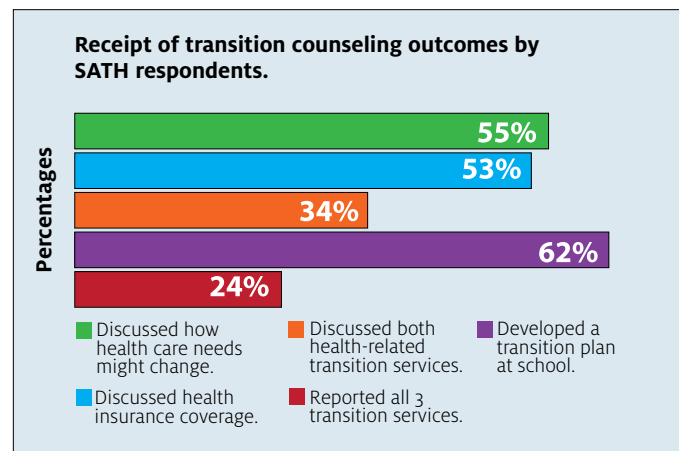
Since Dr. Koop framed the importance of health care transition in transition to adulthood, in 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians–American Society of Internal Medicine issued a consensus statement emphasizing the roles and responsibilities that health care providers have in helping youth with disability-related health care needs transition.

The consensus statement emphasized that providers (primary care and specialty care) are a good focal point of coordination because, in most cases, they have an understanding of the patient’s history, abilities, and priorities. Given their established relationship with the patient, providers need to understand the rationale for health care transition planning as well as have the knowledge and skills to facilitate that process.¹⁶

Challenges to Purposeful, Planned Health Care Transition Planning – The Reality

Despite the increasing visibility of and support for quality, intentional health care planning, challenges remain for youth with chronic health conditions and other disabilities and their families. For example, many health care professionals have not fully adopted health care transition planning into their practices, and if they do, they are not trained to contribute to employment transition planning. As Dr. Santi K.M. Bhagat, Founder and President of (Physician-Parent Caregivers) explains, **“Physicians receive very little information about transition to work. In addition to lack of knowledge, physicians struggle with lack of time.”**

In the 2007 Survey of Adult Transition and Health (SATH), a nationwide survey of young adults aged 19 to 23 conducted by the Center for Disease Control and Prevention’s National Center for Health Statistics, 55 percent reported that their physician or other health care provider had discussed how their needs would change with age. Fifty-three percent reported discussions about how to obtain health insurance as an adult; 34 percent reported that they discussed both health-related transition services; and 62 percent of the respondents reported having a plan on what to do after high school. Only 24 percent, however, reported having received all three transition-counseling services as shown on the chart in the next column:



Source: Sawicki, G.S., Whitworth, R., Gunn, L., Butterfield, R., Lukens-Bull, K., Wood, D. Receipt of Health Care Transition Counseling in the National Survey of Adult Transition and Health. *Pediatrics* 2011; 128; e521.

The SATH survey findings, however, underscored the individual relationship between an adolescent or young adult and his or her health care team, as a key factor promoting education, trust, and transition planning. Youth who had a regular source of care, such as from a physician and/or nurse, were more likely to receive counseling on their future needs. Better communication with health care providers was also associated with higher odds of reporting a school-based transition plan that articulated what steps the young person needed to take to achieve their post-secondary education or employment goals.¹⁷

The American Academy of Pediatrics’ clinical report entitled, *Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home*, states widespread implementation of health transition supports as a basic standard of high-quality care has not been realized for many reasons. A recent national survey revealed that pediatricians remain poorly informed about the conclusions of the consensus statement noted above and that most pediatric practitioners neither initiate transition planning early in adolescence nor offer transition-support services. These services have been found to be critical for ensuring a smooth transition to the adult health care model. The survey authors noted that, “... gaps in transition support are due in part to limited staff training; lack of an identified staff person responsible for transition; financial barriers; and anxiety on the part of pediatricians, adolescents, and their families about planning for their future health care.” Other authors have cited the lack of developmentally appropriate tools for assessing child and family readiness for transition as a barrier to transition.¹⁸

In addition, evidence indicates that many adult providers feel unprepared to care for young adults with complex chronic conditions. In some cases, there is no identified adult primary care or specialty provider to whom care can be transitioned. Low expectations, lack of time, adequate payment, and training have been cited as major barriers to transition. As a physician observed to the study team, **“Doctors are encouraged to do procedures and order every test in the book to cover them. Helping your patients with anything beyond that is not reimbursable or something you are paid for.”**

There are a few contributing factors that create these system challenges. First, according to the Association of American Medical Colleges, there are the existing and anticipated workforce shortages for physicians and other health professionals. In the face of an aging population that needs care, these shortages may be an obstacle to the delivery of primary care to more young adults with or without disability-related health care needs. This makes addressing the Nation’s physician shortage - projected to climb to more than 90,000 by 2020 - more important than ever.

Second, although the health care system has a direct impact on transition planning as it applies to a youth’s self-care and health management for a chronic health condition or other disability, it is less connected to the role of transition as a pathway to work. Health care professionals tend to focus on biological and physiological assessments to diagnose and treat rather than adopting a biopsychosocial approach. The biopsychosocial approach combines three interrelated concepts - that go beyond the individual’s “disabling condition” - and considers physical, emotional, and environmental factors.¹⁹

One of the areas identified in the research where the focus solely on biological and physiological assessment can be detrimental is in the making of medical diagnoses needed for youth to qualify for Social Security disability benefits. Health care professionals tend to learn about Social Security and other public assistance programs that can impact employment transitions through informal channels – from peers and even patients. As an example, a pediatrician interviewed confided that she learned how to complete Social Security disability forms from a resident during her training. In her words, “He told me which box meant the patient would qualify for benefits and which one wouldn’t.” Even though this procedure may be seen as a simple biological and physiological assessment, it demonstrates how assessments performed by health care professionals create circumstances that significantly

influence patients’ understanding of their level of functioning and their perceptions of their ability to work.

Despite the intent behind the Social Security Systems’ employment support provisions such as the Ticket to Work and the Plan to Achieve Self Sufficiency, the current infrastructure also creates disincentives that inhibit transition planning. The potential of losing financial benefits, and most importantly, health insurance, discourages youth with disabilities from seeking employment. According to John G. Reiss, PhD, Associate Professor, Institute for Child Health Policy, University of Florida, **“The way Social Security disability benefits are determined has parents focused on inability. If a child does well, you may lose support since Social Security Disability Insurance (SSDI) is associated with eligibility for Medicaid. It’s an adverse incentive.”**

Furthermore, an analysis by the Social Security Administration determined that individuals are likely to remain on benefits for 27.1 years when their participation begins around age 18 (Social Security Administration, 1996) consigning many youth and young adults with disabilities to a lifetime outside of the American workforce. In addition, failure to connect to the workforce in early adulthood has been linked to lower earnings and lower levels of employment later in life.²⁰

Perceptions of systems’ distinct and disparate outcomes and goals also contribute to keeping health care transition and post-school transitions separate. Educators see their responsibility in terms of helping youth move toward independence through educational growth and enhanced skills. Health care professionals see their role as diagnosing, treating, and improving. These challenges are reinforced by perception of federal laws as limiting the exchange of information.

The research further revealed that the design of the current health care systems itself is also problematic. As stated by Donald Berwick, MD.: **“Everyone is working hard, but the quality of chronic care is still mediocre. Every system is designed perfectly to achieve the results that it achieves. The problem is the growing mismatch between the chronic care needs of the population and the acute care orientation of the health care system. The current health care system is designed to treat people’s acute illnesses and injuries. It’s as though we are trying to put a square peg in a round hole. We will continue to get the poor results we are now getting until we redesign the system.”²¹**

FINDINGS

- Families, youth, and health care transition focused professionals recognize that work and health are inextricably linked;
- As more youth with chronic health conditions and disabilities survive into adulthood, there is a greater need for coordinated youth to adulthood transition related services and resources across systems that recognize and incorporate the transition from pediatric to adult health care and vice versa; and
- There are a number of cross system barriers to promoting improved transition experiences for youth. These barriers include: lack of coordination between the transition from pediatric to adult care and the transition from school to work, reduced earnings potential of families as they navigate the transition process, and inconsistent access to health care services.

Opportunities to Transform Health Care Transition Planning through the Affordable Care Act

A number of provisions in the ACA have potential to transform health care transition planning for youth with disabilities and chronic health conditions. The new law reforms the insurance market and provides expanded coverage to millions of Americans, many of whom are uninsured today and being served by Federally Qualified Health Centers. Particularly promising is the ACA's provision that removes disincentives forcing young adults with disabilities to choose between working and potentially earning an income that may have disqualified them from Medicaid. With expanded income eligibility requirements for Medicaid and increased employer-sponsored options, more young adults with disabilities will be able to start or continue working while maintaining their Medicaid coverage.

To support its triple goals of improving affordability, health status, and patient experience, commonly known as the “triple aim”, the ACA includes quality incentive programs, payment reform, the promotion of patient-centered medical homes, and Accountable Care Organizations (ACOs).²² ACOs are groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to the Medicare patients they serve. Coordinated care helps ensure that patients get the right care at the right time, with the goal of avoiding unnecessary duplication of services and preventing medical errors. When an ACO succeeds in both delivering high-quality care and spending health care dollars more wisely, it will share in the savings it achieves for the Medicare program.²³

Furthermore, the ACA includes structural and functional elements likely to enhance the delivery of purposeful, planned health care transition planning services. Some of these include a quality improvement strategy; the linking of patients with specific providers to ensure the continuity of the patient-provider relationship; continuous and team-based healing relationships; organized, evidence-based care; professional development, patient-centered interactions to increase patients' involvement in their own care; and care coordination to reduce duplication of services and decrease anxiety and financial costs for patients and their families.²⁴

Recommendations

Based on its scan of current health care transition planning practices, the study team recommended a two-pronged approach for promoting purposeful planned health care transition planning for all youth, including those with chronic health conditions and other disabilities at the federal, state, and local levels that focused on:

1. Education and outreach for youth, families, and other caring adults; and
2. Professional development for health care professionals that incorporates employment and transition related outcomes.

1. Education and Outreach for Youth, Families, and Other Caring Adults

In order for youth to better understand how to incorporate self-management of health and wellness, and career exploration into health care transition planning, more meaningful education and outreach is necessary. This should include tools and resources to help youth make informed decisions about transfer of care, insurance coverage, self-management of care, school and workplace accommodations, and other supports to obtain an improved quality of life (e.g., career exploration, housing, transportation, benefits planning, etc.).

Because families and other caring adults, including health care providers, play a key role in setting expectations and in motivating youth to reach their fullest potential, education and outreach efforts should also focus on this group. Providing increased access to reliable, quality transition-related resources and tools to make them aware of available options, and to build their confidence about supporting youth through self-determined health care and general transition planning processes are paramount. When families and other caring adults are educated on all options available, they are better able to help youth weigh the pros and cons and determine the “right” choice for them based on their interests, strengths, and abilities.

The education and outreach strategy should draw its core components from evidence-based practices such as the patient-centered medical home model and the *Guideposts for Success*.

2. Professional Development for Health Care and Other Youth Service Providers

Youth who receive coordinated services have the strongest outcomes related to employment, self-sufficiency, and health. Because health care providers are among the many youth service professionals that can influence a young person’s successful transition from youth to adulthood, cross-systems professional development is needed to help ensure that these individuals have the knowledge, skills, and abilities needed to provide comprehensive, continuous, culturally relevant service delivery that is dignified, future-oriented, and youth and family-centered.

To achieve this goal, policymakers will need to work together strategically. Enhancements in infrastructure will be needed to improve education and cross training generally. Moreover, alignment of professional development competencies across systems will also be necessary to facilitate the delivery of purposeful coordinated cross-system transition planning services for all youth including those with chronic health conditions and other disabilities.

Recommendations

This examination of health-care transition planning for youth with disabilities including chronic health conditions demonstrated the need to:

- underscore the interdependence between health and wellness, and employment through education and outreach; and
- provide health-care providers and other youth service professionals with professional development opportunities to gain the knowledge, skills and abilities needed to guide youth through a coordinated self-determined, cross-discipline transition planning process.

Conclusion

This study examined the interdependence between health and wellness, and the transition to work for youth with disabilities including those with chronic health needs. Despite growing recognition of the importance of health care transition in the overall transition from school to work and independent living within the health care community, the study revealed that a number of challenges exist for these youth and their families. Included among these are low expectations, lack of time, inadequate payment and training, systems with distinct and disparate outcomes and goals, and the application of a biological/physiological versus biopsychosocial treatment approach. In addition to identifying a number of provisions in the ACA which have significant potential to transform health care transition planning, the study team recommended a two pronged approach for promoting purposeful planned health care transition planning through education and outreach to youth, families and other caring adults and cross-systems professional development of health care and other youth service providers.

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