

POLICYLAB

EVIDENCE TO ACTION BRIEF | SPRING 2017

TRANSITIONING TO ADULT CARE:

SUPPORTING YOUTH WITH
SPECIAL HEALTH CARE NEEDS



Caren Steinway, Jennifer Gable, Sophia Jan | policylab.chop.edu

PRODUCED IN COLLABORATION WITH CHOP'S MINT PROGRAM

CONTENTS

2

EXECUTIVE SUMMARY

4

BACKGROUND

8

WHAT WE LEARNED

14

WHAT WE CAN DO

24

CONCLUSION

EXECUTIVE SUMMARY

The transition from pediatric to adult health care systems can be daunting for anyone, but is especially challenging for young people with intellectual disabilities or other special health care needs. Children with special health care needs have one or more chronic physical, developmental, behavioral or emotional conditions and require health and related services beyond what children generally require.^{1,2}

The health care transition frequently occurs concurrently with and has major implications for other life changes, such as graduating from high school, entering the workforce or continuing into higher education and living independently. At this time, youth typically lose access to occupational, physical and speech therapies, medical equipment and other services that were covered by insurance or provided in schools. People with complex conditions often need these specialized services to maintain and improve their ability to function.

Figure 1

JOHN'S STORY: TRANSITIONING FROM PEDIATRIC TO ADULT CARE



JOHN IS 23 YEARS OLD AND LIVES WITH DOWN SYNDROME, SLEEP APNEA, HEARING LOSS, HIGH CHOLESTEROL, ADHD, OBSESSIVE COMPULSIVE DISORDER, DEPRESSION AND A HISTORY OF OTHER MEDICAL ISSUES.

He continues to require multiple specialists in addition to a primary care doctor to manage his ongoing medical needs. Although he is an adult, he still sees a pediatrician and mostly pediatric specialty providers because his mom has been unable to get help in identifying adult providers who feel equipped to provide his care. Although she managed to find an adult sleep physician, John's mom is usually told that the adult providers who participate with their insurance are not accepting new patients or do

not have experience caring for individuals with Down syndrome. Therefore, John's care has become extremely fragmented. His mom must coordinate this complicated network of care on her own, and faces not only additional demands on her time and resources, but also an increased sense of responsibility to monitor her son's conditions and determine whether he requires medical attention. At times, this has led to unnecessary testing or lab work because there is no coordination around holistic care.

Challenges during this transition period can lead to lapses in health insurance coverage; reduced access to necessary health care services, medications and equipment; increased use of acute care settings like the emergency department; and loss of independence or functioning.³

Among adolescents with special health care needs:¹

- 62% have difficulty with one or more of the following: feeling anxious or depressed, acting-out, fighting, bullying or arguing, making and keeping friends
- 35% have three or more chronic conditions
- Nearly 30% miss one week or more of school due to their chronic conditions
- 14% have developmental disabilities—including intellectual disabilities, cerebral palsy and autism—that increase their lifelong dependence on family and caregivers
- 3% use or need regular physical, occupational or speech therapy

PolicyLab researchers conducted a series of large surveys and interviewed providers, patients and families to understand the barriers to transitioning young patients with chronic illnesses or disabilities into adult health care, and whether there were any institutional or systems supports in place to aid the process.

In this *Evidence to Action* brief, we identify many of these barriers and provide recommendations for pediatric and adult providers, health care systems, and policymakers to ease the transition process from pediatric to adult care for youth with special health care needs. These policy solutions would help improve overall health outcomes, reduce health care costs and enhance the quality of life for these vulnerable patients and families.

BACKGROUND

Nearly one in five, or approximately 4.3 million, adolescents in the United States have a special health care need, anything ranging from asthma to childhood cancer.¹⁴ At Children's Hospital of Philadelphia (CHOP), more than 44,000 patients are over the age of 18, many of whom are medically complex or have an intellectual disability. While several factors can delay or prevent the transition of young patients—both those who are generally healthy and those who have special health care needs—into adult health systems, the process can be much more difficult for individuals who need specialty care. Not only do these young adults need to see appropriate providers who can adequately address all of their adult medical needs, but their continued use of services at CHOP means there are fewer resources available for babies, children and younger adolescents.

Additionally, as researchers and scientists continue to make lifesaving and life-extending advancements in medicine, increasingly more children with serious and previously fatal conditions are living into adulthood.⁵ For adult providers, these recent advancements have increased the need for expertise in treating conditions that were once exclusively seen in pediatric settings, such as cystic fibrosis or sickle cell disease, but available training has not yet caught up with the demand. For the patient, the transition from pediatric to adult health care can add stress to or complicate the other significant life changes they are concurrently experiencing, such as graduating high school, entering the workforce or heading to college.

Accessing appropriate medical services is complicated for youth with special health care needs. Many see multiple specialists, sometimes in different health care systems. It takes time and resources to coordinate the services received at all of these different points of care. There are often numerous office visits, telephone calls, emails and hospitalizations that surround the transition of care, creating a complex web of communication between providers, institutions and the patient and family (Figure 2).

In order to meet the need for this type of complicated and costly care, most youth with very complex medical needs rely on comprehensive, child-specific benefits of Medicaid—either as the sole source of insurance coverage or to supplement limited private coverage. Medicaid benefits for children include Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services—a federally mandated set of benefits that provides comprehensive coverage for all medically necessary services to correct or ameliorate defects and physical and mental conditions for youth under the age of 21.⁶

In addition, youth with special health care needs benefit from Title V funding and services. Title V is a federal program that provides additional supports to these families, complementing the Medicaid program. This program helps to facilitate the development of coordinated systems of care, as well as primary and preventive care for nearly one million children with special health care needs. Unfortunately, youth age out of these child-specific benefits when they turn 21, which further complicates the transition into adult health care.⁷

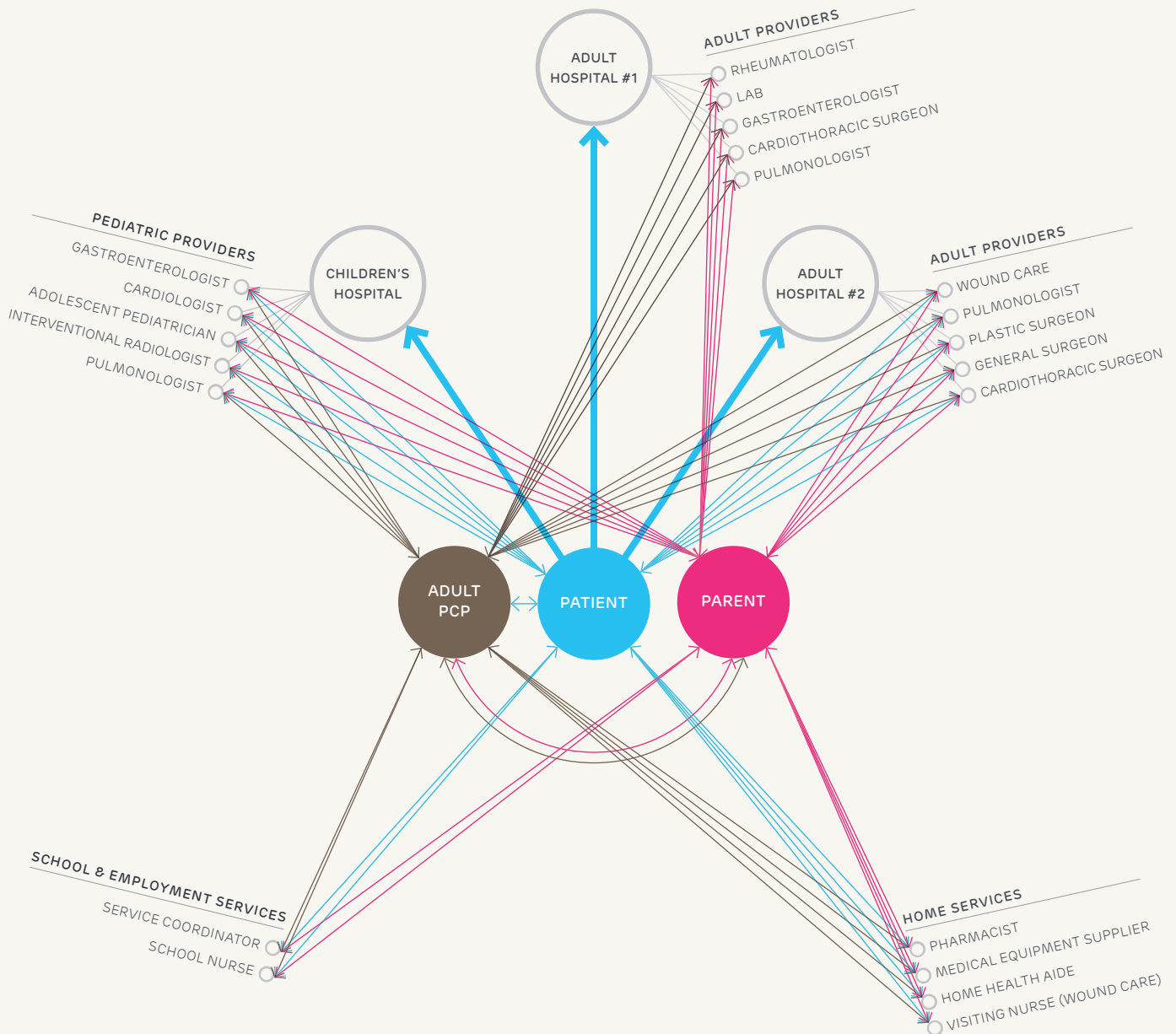
In recognition of the importance of coordinated transition and transfer of care from pediatric to adult medical settings for young adults with medical complexity, the National Center for Health Care Transition (Got Transition),⁸ the leading center on transition from pediatric to adult health care, developed a national standard to help inform the process. Their “Six Core Elements of Health Care Transition” (Figure 3) identifies the most important components of the transition process, and offers guidelines for implementation that providers can interpret and apply to meet the unique needs of each patient.

Although this guidance is readily available, we know that it is not consistently implemented in pediatric and adult medical settings across the country. Many young adults with special health care needs face potentially life-threatening barriers to getting the care they need, such as lapses in insurance coverage, not seeing appropriate providers, and losing access to necessary medications and medical equipment, among many other issues. Little research has been done to determine how the guidelines are being used in practice or to identify the barriers to and facilitators of successful overall transition of care.

Figure 2

COMPLEX WEB OF COMMUNICATION

This complex web of communication illustrates the real-life experience of Michael, a 21-year-old with a complex medical history. His transition from pediatric to adult care included both outpatient and hospital visits across pediatric and adult settings. Michael was born with a rare genetic condition that resulted in multiple birth defects and has led to a lifetime of procedures and ongoing treatments. His experience transitioning from pediatric to adult care represents the challenges that many individuals with complex medical needs face.



Adult PCP

— Email or Phone Call

Patient

— Hospitalization
— Office Visit

Parent

— Email or Phone Call

Figure 3

GOT TRANSITION SIX CORE ELEMENTS

Recognizing the challenges that youth with special health care needs face as they transition out of pediatric care, the Maternal and Child Health Bureau—part of the U.S. Department of Health and Human Services' Health Resources and Services Administration—and The National Alliance to Advance Adolescent Health formed a cooperative agreement called Got Transition in 2005. This collaborative aimed to break down these barriers through innovative strategies for health professionals, youth and families. Got Transition developed six core principles to guide the transition process.

Source: *GotTransition.org. About Got Transition. <http://www.gottransition.org/about/index.cfm>. Accessed January 5, 2017.*



THE DEVELOPMENT AND IMPLEMENTATION OF A TRANSITION POLICY. Health care systems, along with input from families and youth, should develop a policy addressing the system's approach to the transition process. Health system staff should be educated on the policy and their roles in transition. The policy should be shared with youth and families beginning at age 12 to 14.



A SYSTEM OF TRANSITION TRACKING AND MONITORING. Health care systems should develop a process for identifying patients ready to begin at age 12 and follow them through the transition process. A systematic transition registry should be created to track transition progress. Integration with the electronic medical record (EMR) is preferable.



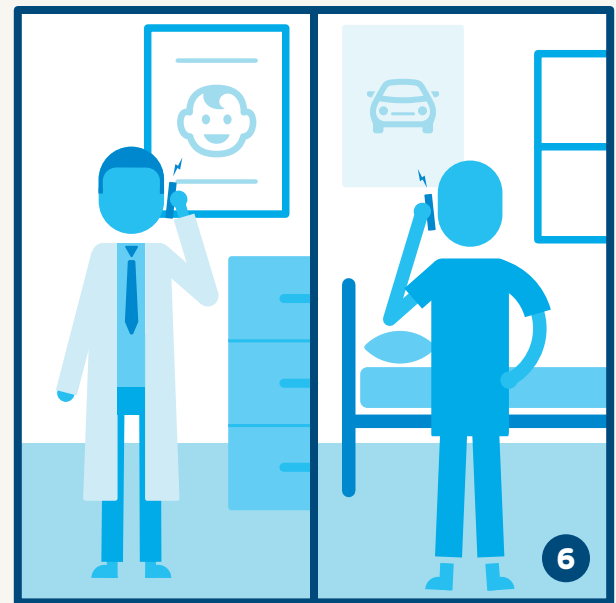
ASSESSMENT OF TRANSITION READINESS. The provider should conduct regular transition readiness assessments of patients beginning at age 14. Patients and providers should communicate about readiness and jointly develop transition goals that promote self-advocacy and self-care.



TRANSFER OF CARE. Pediatric providers should confirm the first adult provider appointment, transfer the patient when he or she is stable and prepare a transfer package, including the final transition readiness assessment, plan of care, medical summary and emergency care plan. The package should be sent to the identified adult provider.



TRANSITION PLANNING. Patients and providers should develop and regularly update the patient's transition plan of care. Providers should prepare patients for an adult approach to care at age 18. Patients, caregivers and providers should discuss the need for decision-making supports for youth with intellectual disabilities, optimal time of transfer and the identification of adult providers. Linkages to insurance and other resources should be provided.



TRANSITION COMPLETION. Pediatric providers should follow-up with patients and caregivers three to six months after the last pediatric visit to confirm transfer of care. Pediatric and adult primary and specialty care doctors should continue to build collaborative partnerships.



WHAT WE LEARNED

PolicyLab researchers and colleagues sought to better understand the challenges of the transition process from the perspectives of patients and families, pediatric providers, and adult providers.

In 2011, we conducted a national survey of adult providers who frequently cared for adult patients with pediatric chronic conditions.⁹ Additional surveys and interviews between 2014 and 2016 included CHOP pediatric providers, Penn Medicine Health System (Penn) adult providers and patients who had recently transitioned out of the CHOP network.^{10,11} We compared the transition process experienced in these settings with Got Transition's "Six Core Elements of Health Care Transition" (Figure 3), and identified perceived challenges to successful transition into adult care. The barriers found through the CHOP and Penn surveys were consistent with our 2011 national survey, indicating that our key takeaways are likely relevant for many providers across the country.



**PATIENT
PERSPECTIVES**



**PEDIATRIC PROVIDER
PERSPECTIVES**



**ADULT PROVIDER
PERSPECTIVES**

Figure 4

KEY FINDINGS: CHALLENGES FOR PATIENTS AND PROVIDERS IN ADULT CARE SETTINGS



RESOURCES

Adult institutions often have less multidisciplinary support staff in outpatient clinics, such as social workers, care coordinators and nursing staff.

Adult receiving providers often have limited time to review the complete medical history of new young adult patients with special health care needs, and pediatric providers often don't make such a detailed summary available.



WORKFLOW

For patients who use medical transport, there is a lack of flexibility when the transport runs late, leaving patients to reschedule appointments.

Adult institutions often do not have sedation services during medical tests, which children's hospitals routinely provide when necessary.



STRUCTURAL & PHYSICAL SPACE

While pediatric outpatient facilities are built to have space for multiple family members in an exam room, adult outpatient facilities can have inadequate space for wheelchairs and other medical equipment.

For patients with autism or behavioral challenges who would benefit from a quieter waiting area, adult outpatient facilities often lack the extra clinical space to accommodate these needs.



PATIENT PERSPECTIVES

Through interviews conducted with 24 adult patients who transferred out of the CHOP network between 2013 and 2015, we discovered the following common challenges that patients faced during their transition process:¹²

Chaotic transfer and poor care coordination.

Care coordination was the most commonly cited transition concern, especially for patients that required frequent visits with multiple specialists. By the time of transition to adult providers, patients and their pediatric caregivers had long-established routines that accommodated the patient's clinical needs and caregiver logistics, such as medical equipment, work schedules, office visit durations, and physical accommodations and transportation.

When transferring to a new provider, new routines need to be established, and many adult care settings lack the time and resources to coordinate what can be a complicated medical visit.

“I'm trying to do at least two visits at one time [because I am wheelchair-bound and don't live in the city]. I would say that every week I'll have three different appointments back to back. People don't understand how hard it is for me to even get to one doctor's office.”

Poor preparation.

Children and adolescents are rarely expected to recount their medical problems or name their medications and allergies in pediatric settings without support from their parents. Consequently, they are often unprepared to engage with adult health care systems independently as the primary medical decision makers. Patients who have transitioned to adult care often described being surprised and unprepared for the level of autonomy and self-advocacy that adult institutions expected them to have.

“I was highly used to having [the pediatric hospital] remind me...you got to call this [doctor]. You got to call that [doctor]. So I kind of lost that. The most eye opening thing about transition was that I had to coordinate everything myself, like an adult.”

Loss of comprehensive insurance coverage.

Virtually all adolescents with the most complex medical conditions are eligible for Medicaid to help cover the extraordinary cost and level of care they need, which often go beyond the limits of private insurance coverage. Eligibility for the comprehensive set of Medicaid benefits available to children ends at age 21 (Figure 5). Additionally, the Social Security Administration redetermines Social Security Insurance (SSI) eligibility when a child turns 18 using adult disability standards; typically one in three such young adults lose their

SSI benefits¹³ and potentially Medicaid eligibility. Furthermore, young adult patients rarely receive appropriate guidance on switching into an adult health insurance plan prior to losing these services and are often left scrambling for care.

Loss of services.

For certain conditions, such as cerebral palsy, most pediatric health care systems have multidisciplinary clinics where a number of different specialists can evaluate a child at one time, such as rehabilitation doctors, orthopedic surgeons, physical therapists, occupational therapists, speech therapists and dietitians. This is generally not the case in adult health care settings that are not specially equipped to manage patients with these complex conditions.

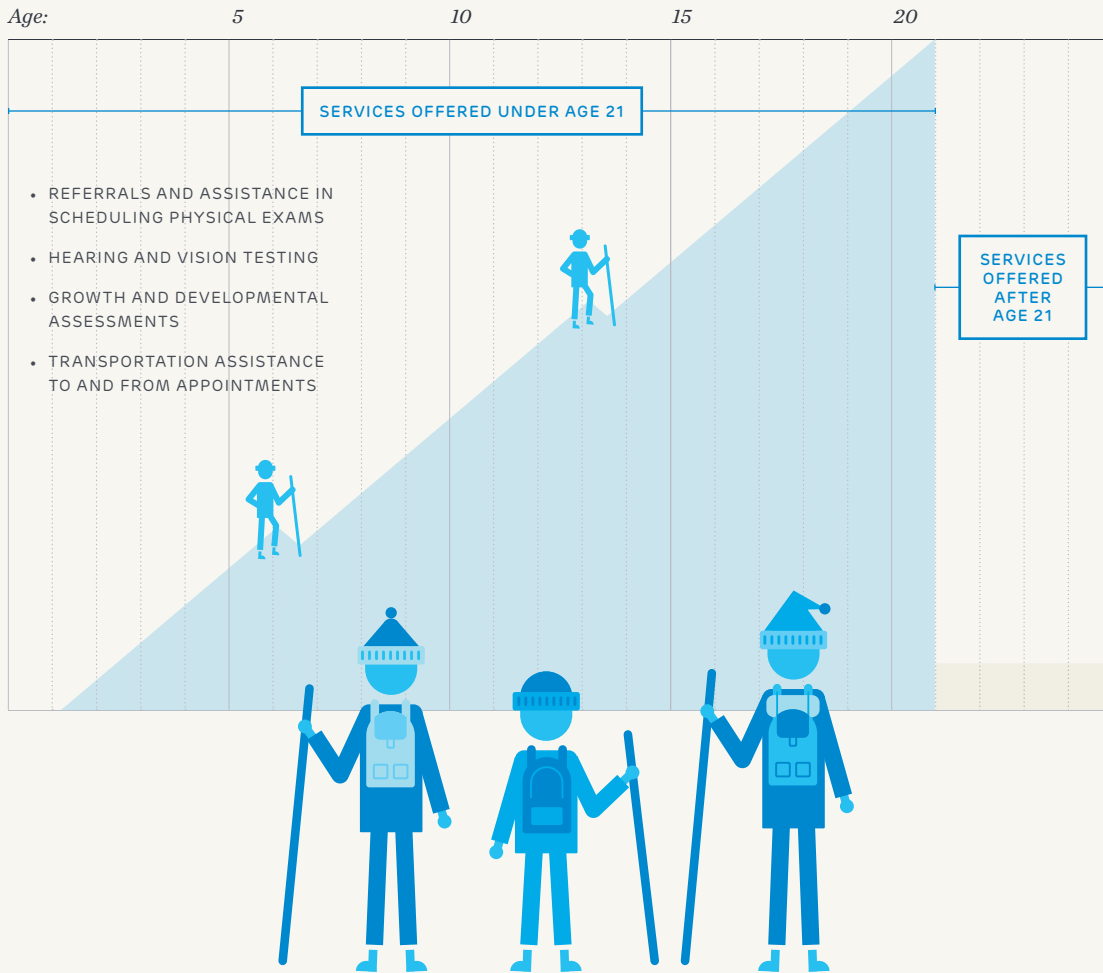
“Once CP [cerebral palsy] clinic at the pediatric hospital is gone, then I no longer have a feeding clinic. And I don’t have PT [physical therapy] or OT [occupational therapy], which I had at school.”

Lack of adult providers.

In transferring to adult health systems, patients and families cite difficulty identifying adult providers and are often left to make laborious phone calls to provider locations. It can be challenging to find a provider that takes their insurance, is accepting new patients and has an understanding of young adults with complex conditions that began in childhood.

Figure 5

FALLING OFF THE EPSDT AND SCHOOL SERVICES CLIFF



DURING CHILDHOOD AND ADOLESCENCE, PATIENTS WITH SPECIAL HEALTH CARE NEEDS RELY HEAVILY ON MEDICAID'S EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT) BENEFIT AND ACCOMMODATIONS PROVIDED IN THEIR SCHOOLS.

Medicaid's EPSDT benefit ensures that children receive screenings to catch potential health problems early, and guarantees coverage of all medically necessary services, meaning those needed to support their development and address physical and mental conditions.

Schools must provide accommodations to help children with special health care needs participate in school activities at their full potential. For example, for some

children, reasonable accommodations include special therapies received during the school day.

After age 21, EPSDT is no longer federally mandated, and youth age out of their school systems. Consequently, coverage and availability of services used to maintain function for individuals with special health care needs—namely physical therapy, occupational therapy and speech therapy—is often discontinued when they reach adulthood.

To evaluate the policies, processes and obstacles surrounding the transfer of care process at CHOP, we conducted a survey of a total of 153 individuals in 2014¹⁴ that compared CHOP transition of care practices against the national standards established by Got Transition. The survey found the following common challenges:

Insufficient time and low adherence to transition guidelines.

Participation in any one of Got Transition’s “Six Core Elements of Health Care Transition” (Figure 3) ranged from 47 percent (having a transition policy) to 13 percent (follow-up after transfer completion). Seven percent of participants did not engage in any of the six core activities of transition. CHOP providers most commonly cited inadequate time as the main reason for not being able to follow national guidelines. Each of these activities take a considerable amount of time, suggesting that additional staffing support is needed for successful routine transition processes. Our finding is consistent with other national surveys that also describe low rates of completing transition activities.^{15,16}

Lack of consensus on transition policies and procedures.

Despite the existence of national guidelines, there was a lack of consensus across all of CHOP’s pediatric primary care and specialty services on if, when and how to transfer patients to adult-focused care, particularly for youth with complex medical needs. Most participants said that the top barrier to transitioning patients was lack of agreement among providers about the transfer process, either within one department or across different specialties. Very few hospitals have transition policies that could address these inconsistent practices and procedures.

Poor documentation of transition discussions or activities in the health record.

Nearly two-thirds of participants did not update the patient’s electronic medical record (EMR) once care was transferred to an adult provider. Of the remaining one-third of participants who did document the transfer in the EMR, few did so in one consistent location within the

record, making it difficult to track and monitor transition practices. Without consistent documentation of the status of transition, other specialty providers in the patient’s care team may not know to also transfer their portion of the patient’s care to the adult providers, potentially further fragmenting the patient’s care. Poor documentation of whether patients have transferred also creates confusion for pediatric emergency room staff, who may not know whether a patient should be treated at the pediatric hospital or be transferred to the adult hospital for appropriate care.

Inadequate access to adult providers with sufficient medical expertise.

Pediatric providers were reluctant to transfer patients to adult providers because they perceived a lack of adult providers who had the desire or expertise to take care of their patients. When adult providers were identified, access to these providers was partly limited by restrictions in provider referral networks included by insurance. For patients with disabilities severe enough to be eligible for SSI and consequently covered by Medicaid, many adult practices or hospital systems did not accept Medicaid or certain Medicaid managed-care products, or may cap the number of patients on Medicaid in that practice, potentially limiting access.

Failure to address medical decision making.

As youth with intellectual disabilities enter adulthood, providers should assess their ability to make medical decisions on their own in order to help them progress towards medical independence or to start the process of establishing a proxy in the form of a legal guardian or formal long-term caregiver. Pediatric providers in our survey reported that they did not conduct such an assessment with their patients about half of the time.

In 2011, we conducted 22 interviews⁹ with adult providers across the country who frequently cared for young adults with pediatric chronic conditions. Nearly all providers in this national study reported that major challenges to caring for new young adult patients with special health care needs included not receiving medical records from a pediatric provider; insufficient time and high administrative burden leading to significant financial constraints; insufficient training and expertise in caring for young adults with pediatric chronic conditions; and poor care coordination and an ill-defined medical team.

In 2016, PolicyLab followed up on the 2014 pediatric provider study with a comparable survey of adult care providers at Penn.¹¹ Similar barriers to a patient’s transition from pediatric to adult care also emerged among these adult providers.

Inadequate time for office visits and care coordination between visits.

Approximately 60 percent of adult providers identified the two largest barriers to taking care of young adults with childhood onset special health care needs to be the amount of time and level of care coordination required during and between office visits. No mechanism currently exists to bill for non-face-to-face care coordination for patients on Medicaid or private insurance, and providers are therefore not adequately compensated for the additional time it takes to effectively manage their patients’ care.

Lack of information on community resources, care coordination reimbursement and legal issues.

Several adult providers echoed pediatric provider concerns that many of them are neither trained nor have experience caring for adults with chronic conditions that begin in childhood. Adult providers regularly requested more

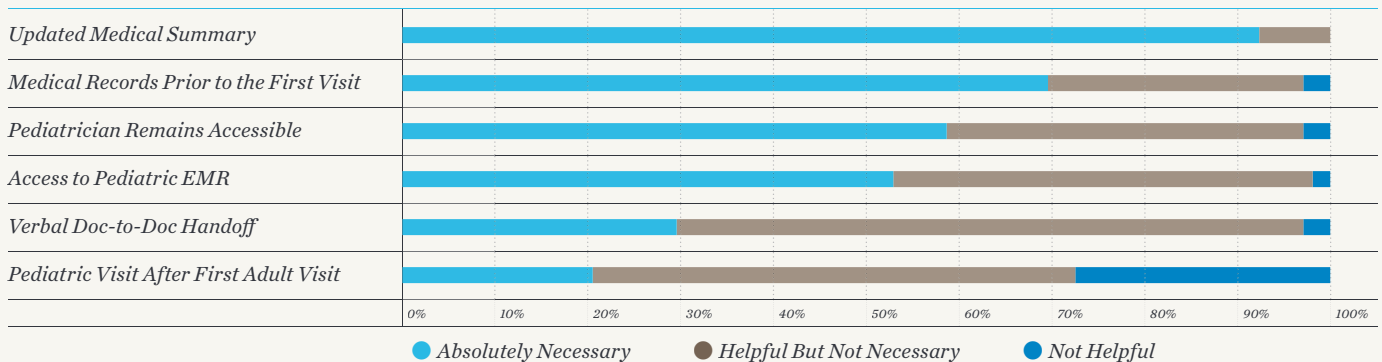
information on a variety of medical conditions, community resources, care coordination, enhanced reimbursement and legal issues, such as guardianship, suggesting a need to educate and map out non-medical resources for adult providers and for young adults with chronic disease.

Inconsistent levels of communication from pediatric providers.

Adult providers indicated that certain types of information from pediatric providers, such as updated medical summaries and patient medical records sent prior to the first adult visit, were absolutely necessary to safely care for a young adult patients with childhood-onset chronic conditions (Figure 6). Only about one in four adult providers said this was always or almost always provided. About 10 percent said it was never available, indicating significant room for improvement in pediatric and adult provider communication and handoffs.¹¹

Figure 6

ADULT PROVIDER OPINION ON NECESSARY COMPONENTS OF PEDIATRIC-TO-ADULT PATIENT HANDOFFS





WHAT WE CAN DO

From our surveys and interviews with patients and providers, we have identified several recommendations that providers, health systems, policymakers and researchers can adopt to improve the outcomes of youth with special health care needs. Some of these solutions directly address problems identified in the studies conducted above, and others have been well defined in the literature around transition to adulthood for young adults with chronic illness or disability.

-  **RECOMMENDATIONS FOR PROVIDERS AND PRACTICES**
-  **RECOMMENDATIONS FOR HEALTH CARE SYSTEMS**
-  **RECOMMENDATIONS FOR POLICYMAKERS**

RECOMMENDATIONS FOR PROVIDERS AND PRACTICES

Health care providers are on the front lines caring for patients, and families of patients, with complex and chronic conditions. Right alongside families, they face the challenges and frustrations of coordinating care and working to ensure that their patients are able to achieve the best possible outcomes. Transitioning care from one network to another, particularly with young adult patients who are learning to manage their own health, is incredibly challenging. This section provides recommendations to address many of these challenges and ensure a smooth transition of care for everyone involved.



PROBLEM 1:

Youth are unprepared to manage their own care, and many youth and their families are unaware of potential loss of services at age 21.



RECOMMENDATION:

Start early in preparing adolescents, or their proxy caregivers, to take on the role of primary medical decision maker in managing their care once they reach adulthood by:

- Better educating youth with chronic illness on their own conditions, self-management and system navigation while still in pediatric settings.
- Regularly assessing transition readiness using the Transition Readiness Assessment Questionnaire. This step is widely recommended by the American Academy of Pediatrics and other professional societies, and is one of the Got Transition six core elements.¹⁷ The information from the assessment can be used to plan education for the patient and family, and communicate the patient’s current skills to other providers. Children and adolescents should be able to identify their medical problems, medications and allergies without support from their parents, or at least know how to access that information.
- Addressing the issue of long-term care needs, including living needs and caregiver support, with caregivers before the patient turns 18.
- Advising parents or other caregivers of youth with intellectual disabilities, as appropriate, to work on building decision-making skills and establish health care supports, proxies or apply for legal guardianship, ideally not long after the patient turns 18.¹⁸



PROBLEM 2:

Lack of communication between pediatric and adult providers, such as neglecting to share written transition summaries, can lead to lapses in care, medical errors and loss of patient trust.



RECOMMENDATION:

Sending and receiving providers should develop methods that facilitate bidirectional communication.

Pediatric providers should consistently generate patient transfer summaries and send them to adult providers prior to the first new patient visit. Much like hospital discharge summaries, which hospital-based doctors are required to prepare for receiving primary care providers, the transition summary is the primary mode of communication between pediatric and adult care teams. The referring pediatric team should write medical summaries that include the current treatment plan, relevant medical and surgical history, relevant medical test results, medications, allergies, nursing care and legal and vocational/academic information. Pediatric providers should also remain accessible to adult providers until transfer of care has been completed.¹⁹

CHOP's Multidisciplinary Intervention Navigation Team (MINT)



MINT is a novel clinical service that provides comprehensive care coordination for patients with complex medical needs transitioning from CHOP to adult health care systems. The team consists of a youth community health worker, social worker, nurse practitioner and physicians. Patients include those who are 18 years and older, have three or more subspecialists or have an intellectual or developmental disability. In addition to coordinating medical care and transfers across multiple specialties, the team also supports young adult patients in developing chronic disease self-management skills, and assists families with long-term care decisions and legal guardianship applications.



PROBLEM 3:

Inconsistent approaches and lack of consensus around transition practices by pediatric providers leads to confusion of youth, their families and the medical team.



RECOMMENDATION:

Consistently follow the transition guidelines developed by Got Transition.

Pediatric practices should establish a transition policy and process that is distributed to patients and families. Policies should set expectations for the time of transfer to adult care and transition procedures along the way, including what activities will occur before transfer and the pediatric provider’s responsibility to create and send a medical summary before the actual transfer occurs. These policies will provide patients and families with a road map that will alleviate much of the uncertainty surrounding the process. Specific activities that patients and families need to do on their own will vary, and providers will guide patients and families in completing any necessary tasks.

Research has shown that the use of checklists and clinical pathways—detailed plans for providers to follow for patients on a specific clinical course with the goal of standardizing care and improving health outcomes—decreases medical errors and ensures that discharge instructions include all necessary information. Transition checklists have been developed and are widely available from organizations such as Got Transition,²⁰ the American Academy of Pediatrics,²¹ the Society of General Internal Medicine and the American College of Physicians.²²



PROBLEM 4:

Poor coordination of medical care during the transition process leads to challenges with maintaining the same high standard of care in the adult health care setting.



RECOMMENDATION:

Develop strategies that improve care coordination, implementation of transition readiness assessments, checklists and clinical pathways, including:

- Identify a health professional or youth advocate—a nurse, nurse practitioner or social worker—to be the transition coordinator between the pediatric and adult practice.²³
- Identify the adult health care team members that each individual will need by collaborating with pediatric specialists involved in each person’s care.
- Utilize transition checklists and transition clinical pathways.²⁴
- Designate a certain clinic session to be a “transition clinic session,” where youth who will be transitioning care in the next six months can learn about planning for the transition process, in order to more efficiently use available resources to assess and manage transition readiness.²⁵
- Assign members of the health care team with specifically transition-related tasks at visits through adolescence and young adulthood.
- Use office waiting time for self-administration of assessment tools and provision of educational information.
- Leverage existing care coordination services for transition purposes.²⁶

Providers and practices can only be as effective as the larger health care systems in which they work. Health care systems are made up of providers and practices specializing in all types of medicine. Health systems also have a governing body that strategically plans for the institution, identifies common themes throughout the organization and sets rules and regulations for the providers and practices that are part of that system. We have identified a number of challenges that patients, families and providers face as a result of inadequate or inefficient processes that are managed by larger health care systems. In order to support providers in carrying out best practices and providing the highest standard of care, this section highlights recommendations for actions that health care systems can take to assist in improving the transition process.



PROBLEM 1:

Institutional barriers prevent interaction between pediatric and adult care providers. Because they are generally siloed, adult providers often have little or no experience managing pediatric-acquired chronic conditions on an individual patient basis.



RECOMMENDATION:

Institutions can enhance opportunities for pediatric and adult providers to interact by eliminating barriers that prevent communication and collaboration in patient care.

Pediatric and adult providers must build collaborative knowledge and trust so that young adults can feel more confident moving from one provider to the other. The goals are for pediatric providers to feel comfortable transferring their patients, and adult providers to feel confident taking charge of their care. Health care systems should use the following strategies to create opportunities for collaborative care with neighboring pediatric and adult hospital systems:

- Organize joint patient care meetings
- Develop combined adult and pediatric continuing medical education opportunities
- Increase the number of dually trained internal medicine and pediatrics (Med-Peds) physicians and dually experienced allied health professionals
- Credential and provide malpractice coverage for certain providers at both pediatric and adult institutions
- Provide flexibility through virtual and in-person consultative services across hospital systems²⁷
- Share read-only access of EMRs across institutions
- Incorporate tools of transition such as transition plans and readiness assessments into EMRs with shared utilization between different providers

Pediatric and adult providers must build collaborative knowledge and trust so that young adults can feel more confident moving from one provider to the other.



PROBLEM 2:

Health systems generally have limited expertise in and availability of resources for complex care management across specialty providers, particularly for rare conditions.



RECOMMENDATION:

Pediatric hospital systems with high volumes of adolescent and young adult patients with chronic illness should designate an entire clinical practice or consulting service to coordinating the transition of young adult patients, particularly those with complex chronic illness.

These specialized clinics and transition teams are not only dedicated to improving care coordination by serving a consultative “quarterbacking” function, but they also usually have enhanced supports (such as dedicated social workers, nurse coordinators or resource experts) and developed more extensive adult provider referral networks. In addition to CHOP’s MINT program (see page 15),²⁸ the following practices are being implemented in other areas.

Nemours A.I. DuPont’s Transition of Care Program

The Nemours Transition of Care program prepares youth for transition to adult care by discussing the patient’s medical condition, specific needs, concerns and aspirations with the patients and family. The program consists of a senior pediatrician and social work coordinator. The team provides families with a written, comprehensive plan with identifiable goals, responsibilities, action items and deadlines. The care plan is shared with all of the patient’s current health care providers, so that all members of the pediatric care team are on the same page at all times.²⁹

Center For Youth & Adults With Conditions Of Childhood (CYACC) at Indiana University/Riley Hospital for Children

CYACC assists youth and young adults in moving from pediatric to adult health care. CYACC employs a multidisciplinary team of social workers, nurses and doctors to assess current aspects of a patient’s life and future needs. Topics addressed include health care provider teams, health care financing, medical decision-making, self-management, health habits, mental health, education, employment, independent living, family/caregiver support, socialization and transportation. The team works with the patient and family to develop a transition plan and goals, and care coordinators assist in carrying out these plans.³⁰

Relative to other adult populations with chronic disease, patients with pediatric-onset chronic conditions represent a small group in most adult health systems. Adult health systems can develop centralized areas of expertise for childhood chronic conditions to improve capacity for managing medically complex young adults. One example of a health system that takes this approach is:

The Transition Medicine Clinic and Baylor’s College of Medicine (TMC)

TMC provides young adults with special health care needs and medical complexity a centralized place to receive coordinated care in an adult health care institution. Recognizing that young adults with special health care needs require additional support, TMC has increased medical and support staff to meet the needs of this

population. By offering a medical home, the staff at TMC work to help patients and families access adult medical care, navigate the adult health care system and maintain or identify alternative social services that are critical to their well-being.³¹



PROBLEM 3:

Inconsistent documentation of transition processes in the medical record and lack of interoperable electronic medical records contribute to poor care coordination.



RECOMMENDATION:

Invest in and utilize EMR supports.^{26,32}

The EMR has great potential to assist in transition planning and facilitation of communication among providers if institutions support the development and use of best practice alerts and resources for transitions of care. These alerts may include transition readiness assessments, documentation templates, educational materials, patient tracking and monitoring dashboards and/or patient education. Health care institutions should invest in EMR transition tools, and health care providers should champion these tools to assist with the transition process.



PROBLEM 4:

Most pediatric medical systems are ill equipped to assess for decision-making support for youth with intellectual disabilities entering adulthood. When health systems do screen for need for decision-making support, there are rarely systems in place to facilitate connection to legal resources.^{18,33,34}



RECOMMENDATION:

Health systems should address means to access and support the decision-making needs of aging youth.

- Health systems may need to collect reports from caregivers and schools, conduct assessments or work with experts such as neuropsychologists and psychiatrists.
- When creating specific supports, health systems should collaborate with legal offices or develop medical-legal partnerships. Specialized legal experts can work directly with patients and families to determine which decision-making supports—such as power of attorney or guardianship—will be needed.



RECOMMENDATIONS FOR POLICYMAKERS

When it comes to ensuring the availability of supports like access to insurance and an adequate pipeline of providers able to take on the growing number of medically complex adults, policymakers must step in to establish the necessary policies and funding structures. This section identifies actions that state and federal policymakers can take to support providers, patients and families through the transition process.



PROBLEM 1:

Young adults aging out of the pediatric health system face challenges accessing adequate health insurance coverage or referral networks to meet all of their special health care needs. ^{36–38}



RECOMMENDATION:

State Medicaid directors should help to prevent the often predictable gaps in health care coverage and access by:

- Employing methods to avert the specific “fall off” from Medicaid coverage as youth age out of children’s coverage for those eligible for ongoing Medicaid coverage as adults with disabilities.
- Extending habilitative services—services needed to maintain function—as part of their guaranteed adult benefits for young adults with complex chronic disease who depend on such services to minimize loss of function and maintain their ability to participate in school or employment.



When it comes to ensuring the availability of supports like access to insurance and an adequate pipeline of providers able to take on the growing number of medically complex adults, policymakers must step in to establish the necessary policies and funding structures.



PROBLEM 2:

Pediatric and adult providers, practices and hospital systems have few incentives to interact with one another or to provide transition services.



RECOMMENDATION A:

The Centers for Medicare and Medicaid Services (CMS) should utilize innovative, consistent and thorough transition payment models that would allow compensation for transition-related services, thus incentivizing their use.

As a result, more providers would talk with patients about the transition process, coordinate care with other specialists and the patient’s new adult providers and enhance the patient experience regarding transition and transfer of care. Innovative transition payment models include:

Enhanced Fee-for-Service (FFS) Payments

In a FFS setting, providers are compensated based on the reporting of medical billing codes. Insurers could enhance current medical billing codes by providing additional compensation (for example, at 150 percent) around the time of transition, recognizing that ensuring successful transfer to adult care requires additional time and work.^{39,40} While billing codes exist for transition services, these are usually not reimbursed by most public and private insurers.³⁹

Pay-for-Performance (P4P)

The P4P mechanism pays providers based on a set of previously agreed upon metrics. In this model, insurers could incentivize pediatric providers to transfer patients before they reach age 22, for instance, and incentivize adult providers to accept complex young adult patients.⁴¹

Capitation

Capitation is the monthly payment for a service. Monthly payments for care coordination services needed for the transition from pediatric to adult health care could ensure that providers are properly compensated for their time preparing the documents for transfer, educating patients and families and communicating with adult providers.

Bundled Payments and Shared Savings

Bundled payments are a group of services that receive one amount of money per episode of care and help align incentives for different providers.⁴² Bundled payments currently exist for transitions from hospital to home, but not for transitions from pediatric to adult health care. Alternatively, savings that the health system incurs through successful transfer could be equally shared with pediatric and adult providers.⁴³ Payments could be linked to completion of services by both the sending pediatric and receiving adult providers.

Administrative or Infrastructure Payments

These types of payments have been utilized by both Medicare and Medicaid. Instead of compensating for direct clinical activities, administrative or infrastructure payments are compensation for

systems change. In the case of transition, these payments could be used for EMR adaptations that include Got Transition’s “Six Core Elements of Health Care Transition” (Figure 3).



RECOMMENDATION B:

Shift care coordination and care management to payers.

Insurance payers are well placed to do this work.^{44,45} By increasing case management staff, insurers can help coordinate patient care and prevent lapses in care. For instance, Pennsylvania Medicaid insurance providers have Special Needs Units to assist patients during the transition process. Case managers typically have established relationships with patients and families and can help identify appropriate adult providers, guide patients and families to appropriate services as the child continues to get older and advocate as needed.



PROBLEM 3:

Youth with complex medical conditions on capitated Medicaid managed care plans are unable to gradually transition care from pediatric to adult primary care providers. Typically, if multiple providers of the same specialty see a patient in the same visit, only one of these providers can bill for services, which creates disincentives for joint visits.



RECOMMENDATION:

CMS, state Medicaid programs and private insurers should create more flexible billing policies to allow both pediatricians and adult primary care providers to bill for the same patient during the transition and transfer process.

Adult providers should have the opportunity to meet and assess pediatric patients in a familiar setting before the transfer process, and then have the opportunity to work alongside pediatric providers if patients are ready for transfer.

Concurrently, managed care plans should improve patient choice. Patients in managed care plans are limited to one practice and one provider network. An example of an innovative solution is the Pennsylvania Medicaid Operations Memorandum.⁴⁶⁻⁴⁸ This memo is a contractual agreement made in 2009 by Pennsylvania’s Medicaid program that gives adolescents with special health care needs in capitated insurance plans the opportunity to see more than one adult primary care provider before they are locked in. This way, patients and families can decide which provider is the best fit for their needs.



PROBLEM 4:

There is an insufficient number of dually trained internal medicine and pediatrics (Med–Peds) clinicians who are ideally suited to provide continuity of care across the lifespan of individuals with pediatric complex chronic conditions.



RECOMMENDATION:

Medicare—which covers the majority of the cost teaching hospitals spend on training medical residents—should increase training opportunities and residency slots for physicians working with medically complex adolescents and young adults.⁴⁹

In the 2015 residency match cycle, there were 380 Med–Peds resident slots at 78 institutions across the U.S. Med–Peds residents comprised less than two percent of all residents in all specialties through the National Residency Matching Program. An increase in the number of residents who specialize in Med–Peds would create a pipeline of providers that have the expertise to care for patients with pediatric-onset chronic illness across the lifespan. Family medicine residencies should also add core competencies in providing primary care for persons with pediatric chronic conditions, which would increase provider knowledge and comfort in managing complex young adult patients.



PROBLEM 5:

There are few opportunities to rigorously study and compare innovations to improve the quality of pediatric to adult care transitions.



RECOMMENDATION:

The Patient-Centered Outcomes Research Institute (PCORI), an independent organization dedicated to funding research projects that enhance patient, provider and policymaker clarity around informed health care decision making, and the U.S. Department of Health and Humans Services' Agency for Healthcare Research and Quality (AHRQ) should continue to fund research around the transition process from pediatric to adult health care.

For example, PCORI recently announced a funding opportunity entitled, "Management of Care Transitions for Emerging Adults with Sickle Cell Disease." Although national guidelines from Got Transition outline ideal transition goals, little has been done to explore best practices and concrete processes that achieve these goals.



Adult providers should have the opportunity to meet and assess pediatric patients in a familiar setting before the transfer process, and then have the opportunity to work alongside pediatric providers if patients are ready for transfer.



CONCLUSION

Transition from pediatric to adult health care systems is challenging and nuanced, especially for young adults with complex medical histories. Although national standards exist to outline the ideal transition of care, these principles have proved difficult to implement, and many patients and providers report ongoing barriers to successfully navigating the transition process.



Our research and other existing literature show that patients experience loss of specialized services, pediatric providers perceive a shortage of adult providers who can adequately care for their patients and few models exist to facilitate the coordination necessary for successful transfer of care.

Providers, health systems and policymakers should work to address these avoidable barriers. In this *Evidence to Action* brief, we've provided several recommendations for how to do so, including developing transition tools at the provider level; creating methods for collaboration between pediatric and adult providers; providing additional support to adult providers; establishing

alternative methods of payment for transition-related services; and securing additional research funding focused on this area. These concrete action steps can help to ensure that young people with complex medical needs accomplish a smooth and successful transition between pediatric and adult health systems, and continue to receive the care they need to lead full and healthy lives.

THE AUTHORS

Caren Steinway, M.S.W., M.P.H. is a research coordinator at PolicyLab at Children's Hospital of Philadelphia Research Institute.

Jennifer Gable, M.P.A., M.B.E. is a policy associate at PolicyLab at Children's Hospital of Philadelphia Research Institute.

Sophia Jan, M.D., M.S.H.P. is a faculty member at PolicyLab at Children's Hospital of Philadelphia Research Institute, a pediatrician for children with special health care needs and an instructor of pediatrics in the Division of General Pediatrics at CHOP, a general internist at the University of Pennsylvania Health System and a senior fellow at the Leonard Davis Institute of Health Economics of the University of Pennsylvania.

CHOP'S MULTIDISCIPLINARY INTERVENTION NAVIGATION TEAM (MINT)

This publication would not have been possible without the contributions of the following members:

John Berens

Adam Greenberg

Rebecca Kim

Dava Szalda

Symme Trachtenberg

Katherine Wu

ACKNOWLEDGEMENTS

We would like to thank Cynthia Peacock and Mary Ciccarelli for editorial and content advice.

SUGGESTED CITATION

Steinway C, Gable JL, Jan S., and MINT. *Transitioning to Adult Care: Supporting Youth with Special Health Care Needs*. PolicyLab at Children's Hospital of Philadelphia; 2017. Retrieved from http://bit.ly/E2A_TransitionsOfCare

RELATED POLICYLAB RESEARCH

PolicyLab at Children's Hospital of Philadelphia. Preparing for Transition of Aging Youth with Complex Medical Conditions and Intellectual Disability. Retrieved from: <http://policylab.chop.edu/project/preparing-transition-aging-youth-complex-medical-conditions-and-intellectual-disability>.

REFERENCES

- Data Resource Center for Child & Adolescent Health. National Survey of Children with Special Health Care Needs. <http://childhealthdata.org/learn/NSCH>. Published 2009. Accessed January 5, 2017.
- McPherson M, Arango P, Fox H, et al. A New Definition of Children With Special Health Care Needs. *Pediatrics*. 1998;102(1):137–139.
- Bloom SR, Kuhlthau K, Van Cleave J, Knapp AA, Newacheck P, Perrin JM. Health Care Transition for Youth With Special Health Care Needs. *J Adolesc Health*. 2012;51(3):213–219.
- Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity, and impact. *Am J Public Health*. 1992;82(3):364–371.
- Perrin JM, Bloom SR, Gortmaker SL. Increase of Childhood Chronic Conditions in the United States. *JAMA*. 2007;297(24).
- Centers for Medicare and Medicaid Services. Early and Periodic Screening, Diagnostic, and Treatment. <https://www.medicare.gov/medicaid/benefits/epsdt/index.html>. Accessed February 28, 2017.
- Association of Maternal and Child Health Programs. About Title V. <http://www.amchp.org/AboutTitleV/Pages/default.aspx>. Accessed March 10, 2017.
- Got Transition. About Got Transition. <http://www.gottransition.org/about/index.cfm>. Accessed January 5, 2017.
- Szalda DE, Jimenez ME, Long JE, Ni A, Shea JA, Jan S. Healthcare system supports for young adult patients with pediatric onset chronic conditions: a qualitative study. *J Pediatr Nurs*. 2015;30(1):126–132.
- Steinway CM, Jan S, Greenberg A, Trachtenberg S. 249. Quality of Care Transition From Pediatric to Adult Care: Measuring Transition Care Processes in a Large, Urban Children's Hospital. *J Adolesc Health*. 2015;56(2):S127.
- Berens JC, Steinway C, Szalda D, Jan S. Transition to Penn Medicine: a survey of adult providers assessing the needs and barriers surrounding a seamless transition process. Poster presented at: 8th Annual Health Care Transition Research Consortium Research (HCTRC) Symposium; 2016; Houston, TX.
- Greenberg AS, Jan S, Szalda D, et al. Transfer Engagement Lessons Learned (TELL): Using Patient Perspectives to Inform and Improve Transition Processes. *J Adolesc Health*. 2016;58(2):S75.
- Social Security Matters. Helping Young People with Disabilities Successfully Transition to Adulthood. <http://blog.ssa.gov/helping-young-people-with-disabilities-successfully-transition-to-adulthood/>. Published September 8, 2016. Accessed March 29, 2017.
- Steinway CM, Jan S, Greenberg A, Trachtenberg S. 249. Quality of Care Transition From Pediatric to Adult Care: Measuring Transition Care Processes in a Large, Urban Children's Hospital. *J Adolesc Health*. 2015;56(2):S127.
- Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: results from the 2005–2006 National Survey of Children With Special Health Care Needs. *Pediatrics*. 2009;123(1):e145–52.
- Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005;115(6):1562–1568.
- American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2011;128(1):182–200.
- Herzer M, Goebel J, Cortina S. Transitioning cognitively impaired young patients with special health needs to adult-oriented care: collaboration between medical providers and pediatric psychologists. *Curr Opin Pediatr*. 2010;22(5):668–672.
- Cooley W, Sagerman P. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182–200.
- Got Transition. Sample Transfer of Care Checklist. <http://www.gottransition.org/resourceGet.cfm?id=229>. Published 2014. Accessed January 5, 2017.
- American Academy of Pediatrics, Illinois Chapter. Transition Checklist for Parents/Caregivers. <http://illinoisAAP.org/wp-content/uploads/CAREGIVER-CHECKLIST.pdf>. Published 2014. Accessed March 29, 2017.
- American College of Physicians. Pediatric to Adult Care Transitions Initiative. <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative>. Accessed March 29, 2017.
- Kelly D. Theory to reality: the role of the transition nurse coordinator. *Br J Nurs Mark Allen Publ*. 2014;23(16):888, 890, 892–894.
- Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. *Prog Transpl*. 2006;16(4):291–302.
- Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between pediatric and adult healthcare: a systematic review. *Arch Dis Child*. 2011;96(6):548–553.
- Szalda DE, Jimenez ME, Long JE, Ni A, Shea JA, Jan S. Healthcare system supports for young adult patients with pediatric onset chronic conditions: a qualitative study. *J Pediatr Nurs*. 2015;30(1):126–132.
- Hall CL, Newell K, Taylor J, Sayal K, Swift KD, Hollis C. “Mind the gap”—mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*. 2013;13:186.
- Children's Hospital of Philadelphia. Transition to Adulthood Program. <http://www.chop.edu/centers-programs/transition-adulthood-program>. Published May 5, 2014. Accessed March 2, 2017.
- Nemours Children's Health System. Pediatric Transition of Care. <https://www.nemours.org/service/medical/transitionofcare.html?location=naidhc>. Accessed March 2, 2017.
- Riley Hospital for Children at Indiana University Health. Center for Youth & Adults With Conditions of Childhood. <https://www.rileychildrens.org/departments/center-for-youth-adults-with-conditions-of-childhood>. Accessed March 2, 2017.
- Berens JC, Peacock C. Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions. *J Pediatr Rehabil Med*. 2015;8(1):3–12.
- Dufendach KR, Eichenberger JA, McPheeters ML, et al. *Core Functionality in Pediatric Electronic Health Records*. Rockville, MD: Agency for Healthcare Research and Quality (US); 2015. <http://www.ncbi.nlm.nih.gov/books/NBK293626/>. Accessed March 29, 2017.
- Camfield P, Camfield C. Transition to adult care for children with chronic neurological disorders. *Ann Neurol*. 2011;69(3):437–444.
- Davies MD, Beamish W. Transitions from school for young adults with intellectual disability: Parental perspectives on “life as an adjustment.” *J Intellect Dev Disabil*. 2009;34(3):248–257.
- National Center for Medical–Legal Partnership. Milken Institute School of Public Health. <http://medical-legalpartnership.org/>. Accessed March 29, 2017.
- Goudie A, Carle AC. Ohio study shows that insurance coverage is critical for children with special health care needs as they transition to adulthood. *Health Aff Proj Hope*. 2011;30(12):2382–2390.
- Dowshen N, D'Angelo L. Health care transition for youth living with HIV/AIDS. *Pediatrics*. 2011;128(4):762–771.
- Williams B, Tolbert J. Aging Out of Early and Periodic Screening, Diagnostic and Treatment (EPSDT): Issues for Young Adults with Disabilities. <http://kff.org/medicaid/issue-brief/aging-out-of-early-and-periodic-screening/>. Published December 21, 2006. Accessed March 29, 2017.
- McManus M, Turchi RM. Coding, payment options for pediatric to adult care transition services. *AAP News*. 2015;36(9):10–10.
- Bindman AB, Blum JD, Kronick R. Medicare's Transitional Care Payment—A Step toward the Medical Home. *N Engl J Med*. 2013;368(8):692–694.
- James J. Health Policy Brief: Pay-for-Performance. http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=78. Published October 11, 2012. Accessed March 29, 2017.
- Centers for Medicare and Medicaid Services. Bundled Payments for Care Improvement (BPCI) Initiative: General Information. <https://innovation.cms.gov/initiatives/bundled-payments/>. Accessed March 29, 2017.
- McStay F, Patel K, McClellan MB, George M, Hart R, Farmer SA. A case study in payment reform to support optimal pediatric asthma care. <https://www.brookings.edu/research/a-case-study-in-payment-reform-to-support-optimal-pediatric-asthma-care/>. Published April 27, 2015. Accessed March 29, 2017.
- Patient Centered Medical Home Resource Center. Coordinating Care for Adults With Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions. <https://pcmh.ahrq.gov/page/coordinating-care-adults-complex-care-needs-patient-centered-medical-home-challenges-and#tocChp5>. Published January 2012. Accessed March 29, 2017.
- Barry SA, Teplitsky L, Wagner DV, Shah A, Rogers BT, Harris MA. Partnering with Insurers in Caring for the Most Vulnerable Youth with Diabetes: NICH as an Integrator. *Curr Diab Rep*. 2017;17(4):26.
- Pennsylvania Medical Home Initiative. OPs Memo. <http://www.pamedicalhome.org/ops-memo>. Accessed March 29, 2017.
- The PEAL Center (Parent Education & Advocacy Leadership Center). Special Health Care Needs. http://www.pealcenter.org/help-special_needs.php. Accessed March 29, 2017.
- ACHIEVA. Healthcare Transition: Pediatrics to Adult Medical Systems. <https://www.achieva.info/healthcare-transition-pediatrics-adult-medical-systems>. Published July 7, 2014. Accessed March 29, 2017.
- Association of American Medical Colleges. Medicare Resident Limits (“Caps”). https://www.aamc.org/advocacy/gme/71178/gme_gme0012.html. Accessed March 29, 2017.

PolicyLab *Evidence to Action* briefs highlight PolicyLab research and propose evidence-based local and national policy solutions to advance child health and well-being.

The mission of PolicyLab at Children's Hospital of Philadelphia is to achieve optimal child health and well-being by informing program and policy changes through interdisciplinary research.

Founded in 2008, PolicyLab is a Center of Emphasis within the CHOP Research Institute, one of the largest pediatric research institutes in the country. At PolicyLab, our experience caring for children and families informs our “evidence to action” approach to improving children’s health.



PolicyLab

Children's Hospital of Philadelphia
3401 Civic Center Boulevard
Roberts Center, 10th Floor
Philadelphia, PA 19104

P 267-426-5300

F 267-426-0380

PolicyLab@email.chop.edu
policylab.chop.edu

 @PolicyLabCHOP