
Policy Brief: Ensuring Successful Transitions to Adult Care for Young Adults with Special Healthcare Needs



NATIONAL
PARTNERSHIP FOR
PEDIATRIC TO ADULT
CARE TRANSITION

EXECUTIVE SUMMARY

Insufficient infrastructure and processes in the healthcare system create significant stress for patients transitioning from pediatric to adult care. Young adults with complex medical needs face particularly high barriers, often requiring additional resources and support throughout this challenging transition.

The differences between pediatric and adult healthcare systems exacerbate these barriers. There is often limited coordination between pediatric and adult care providers, and few healthcare systems employ dedicated staff to streamline transitions. This lack of support prolongs the transition process and increases the burden on patients and families. Moreover, complex cases demand extended time commitments, yet insurance reimbursement often fails to adequately cover the necessary procedures. Compounding this issue, there is a shortage of adult physicians and specialists who are knowledgeable about the needs of patients with conditions that originated in childhood.

To address these challenges, policy action is essential. New policies that support coordinated care and resource allocation can bring us closer to eliminating the “care cliff” for young adults with complex healthcare needs as they transition to the adult healthcare system.

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BACKGROUND

In the last few decades, there has been monumental success in extending the lives of patients with pediatric-onset conditions. New forms of medical advancements, specialized care, early diagnosis, and improved therapies have prolonged the lives of many patients with life-threatening conditions.¹ As a result of improved survival rates, there are now more patients with pediatric-onset conditions living well into adulthood.²

The population, defined as Children and Youth with Special Healthcare Needs (CYSHCN) by the Maternal and Child Health Bureau in 1998, comprises a large portion of the pediatric population. The care regimens of these youth normally require multiple providers and strong coordination for care, which can create cost barriers for families and caregivers. Geographic gaps in care are also likely to affect care access. Children with Special Healthcare Needs are more likely to have unfulfilled medical needs due to the extensive care needs required.

The Health Resource and Services Administration (HRSA) states that approximately 1 in 5 children in the United States have special healthcare needs, a number more prevalent for children in impoverished communities.³ This accounts for approximately 4.3 million adolescents overall. Youth with chronic conditions also make up a large portion of the transition-age population. 25% to 35% of the 65 million in the age period for pediatric to adult transition have at least one chronic condition.⁴

The improved quality of life and longevity for children with special healthcare needs are things that need to be celebrated. However, this success has created new challenges. More patients than ever require lifelong care management. And despite the many patients with pediatric-onset conditions, the American Healthcare system has largely failed to keep up.

Among one of the largest challenges for pediatric patients with complex conditions is the transition to the adult healthcare system. As complex pediatric patients leap from the mostly familiar pediatric system, they are regularly met with multiple challenges that can prevent them from accessing adequate care in adulthood. This so-called “care cliff” affects many pediatric patients and is not singular to one condition.

Gaps in care and inefficient patient resources demand a calculated response that ensures our health systems and providers can meet the comprehensive needs of pediatric patients transitioning to adult care. As stakeholders work to achieve efficient healthcare transitions, patient needs and care must be prioritized.

PATIENT PERSPECTIVES

Janay H.

(MI, Hydrocephalus)

“My pediatric neurosurgeon abruptly retired without a warning. This led to the search for a new neurosurgeon. Despite multiple consultations, no adult neurosurgeon was interested in taking me due to the complexity of my hydrocephalus. At that time, I had over 20 brain surgeries. After over a year of difficulties, I finally found an adult neurosurgeon who agreed to take me as a patient. I was lucky since my shunt did not malfunction during that time. If it did, I would have been sent to a hospital for a shunt revision surgery with a neurosurgeon who was unfamiliar with the complexities of my medical history. This period of transition left my family and me with high amounts of stress, anxiety, and depression. This prolonged period without adult providers could have been life-threatening.”

Zack T.

(TX, Arthritis)

"When I went to doctor's appointments around 17 and 18, I remember the doctor looking past me and speaking directly to my mom or grandma. It was a funny feeling where I'm almost an adult and I'm feeling excluded from these conversations with my doctor about my condition. I had to speak to my doctor and my caregivers about giving me the autonomy to be able to learn about my condition and make decisions that would directly affect my care."

Jessica C.

(FL, Hydrocephalus)

I aged out of the pediatric system at 21. As soon as I aged out, my pediatric system, my adult neurologist, and my neurosurgeon gave me a list of providers. The task was left up to my mom and I to coordinate on our own. Finding new providers proved extremely challenging. And it took many hours of grueling research. I first had to find medical professionals who were located in close proximity as I could not drive due to my condition. Many providers were also not interested in taking me as a patient due to my Medicaid coverage and complex medical history. I finally found a PCP and neurologist to accept me as a patient. However, I have to drive pretty far when I need to see my adult neurosurgeon. Lack of understanding on the adult provider side created many barriers to me finding accessible care.”

LANDSCAPE

Although the American Academy of Pediatrics recommends that pediatric patients transition out of the adult system between the ages of 18 through 21, some patients retain access to pediatric care teams well into adulthood.⁵ Patients prefer this due to a variety of reasons.

Pediatric providers have stronger expertise on pediatric-onset conditions compared to adult providers. If a patient's pediatric provider is available to accompany them into adulthood, there aren't incentives to switch. Maintaining a relationship with a provider also ensures consistency. This eliminates any possible life-threatening gaps in care that may come during the transition period. Lastly, pediatric patients with complex conditions are more likely to have strong relationships with their care team. Extensive care demands mean that more time is spent together. The specialized understanding of the patient's medical history and care regimen establishes high levels of trust.

In summary, patients value the comfort and trust that has been developed through time. Although this option is utilized for some patients with onset pediatric conditions, it is not an option for most. Most hospitals and clinics implement policies that end patients' eligibility for pediatric care when reaching a certain age. If patients have not prepared years in advance, they can feel unprepared and limited in finding much needed care.

Key differences between the adult and pediatric healthcare systems may uncover some of the forces behind the "care cliff". While pediatric systems provide many accommodations, the adult healthcare system largely shifts responsibility to the patients. Shifts in care communication and coordination can create new challenges.

Help is rarely provided to schedule consultations and assist with appointment reminders in the adult system. Many patients lack assistance with finding new providers during transitions in care. The new role of managing care can come as a heavy task for newly transitioning patients, a challenge more difficult for those with developmental or cognitive disabilities.

Transitioning youth with multiple chronic conditions must coordinate with different physicians. Unlike pediatrics, adult specialists are not always located in the same health system. Patients must engage with multiple practices and hospitals to manage their care regimen, a task that can be exhausting and confusing. The coordination of care may suffer if they are not fully prepared for these demands.

Adult patients are expected to make care decisions for themselves, which differs from pediatric settings where caregivers have the primary role. Parents generally lose automatic access to their child's adult visits. A patient must also confirm authorization for parents to retain access to medical records as they turn 18. The rules, often unknown by caregivers, can come as a surprise thus affecting the continuity of care.

The adult healthcare system's lack of accommodations for adult patients with disabling conditions also affects the transition of care.⁶ Despite protections established by the Americans with Disabilities Act (ADA) and the Affordable Care Act (ACA), adults still experience healthcare discrimination. In 2022, 40% of adults with disabilities reported unfair treatment within healthcare settings.⁷ Bias and discrimination can significantly worsen care outcomes for patients with disabilities.

Structural factors contribute to adult healthcare gaps for those with disabilities. Physicians lack understanding of the Americans with Disability Act which can affect their compliance with the law's provisions.⁸ Many adult providers lack access to equipment (exam tables, scales, and exam chairs) which prevents patients from receiving efficient care.⁹ Clinical settings, especially those in rural areas, do not have accessible infrastructure. Patients even have trouble accessing transportation to get to clinical visits and consultations.

Additionally, reporting has shown the effect of inherent healthcare bias on children with special needs involved in the pediatric-to-adult healthcare transition. A study by Health Affairs uncovered that disabilities act as a major factor preventing physicians from selecting new patients. Adult patients with disabling conditions were cited as burdensome to clinicians.¹⁰ Many believed new investments into accommodations were not worth the cost due to the small number of patients it would impact. Extensive medical needs were explained as a disruption to clinical schedules. Others felt they or their practice could not address the needs of patients with disabilities.¹¹

The underlying bias impacting adult care has large implications for transitioning youth. Patients struggle to find providers who have proper accommodations within their clinics. Providers can turn down transitioning youth due to low confidence levels in treating patients with disabilities. In reference to the Health Affairs report, many adult physicians do not see themselves as “the right doctor” for transitioning young adult patients.

Reimbursement Disincentives

Aside from structural healthcare bias, payer decisions may play a large part in HCT barriers. Inadequate reimbursement for recurring/routine procedures and care visits create disincentives for adult providers to take on children and young adults with special needs. Complicated care needs for adult patients require clinicians to invest more time and resources into visits and consultations. Complex patients normally require larger amounts of administrative or follow-up work.

This additional time and administrative burden needed to assess complex patients is not covered by Medicaid or private managed care plans that use traditional fee-for-service reimbursement models. The structure causes physicians to lose money during consultations or procedures.¹² Additionally, certain procedures common for individuals with complex conditions provide low reimbursement levels.

For example, shunt neurosurgeries common for individuals with hydrocephalus receive approximately \$5000 in reimbursement from private payers and \$4800 from public payers.¹³ These reimbursement levels are lower than other procedures commonly performed by neurosurgeons like a Laminectomy, which is billed for approximately \$6,900.¹⁴ Therefore, neurosurgeons possess greater financial benefits accepting patients who require more common, higher reimbursed procedures instead. Largely faced with workload challenges, burnout, and department patient capacities, providers face difficult decisions in who they accept as a patient.

Patients on Medicaid face stronger challenges when looking for new adult providers. The program, which provides lower reimbursement rates than private insurance, has fewer enrolled physicians. Only 74% of physicians report accepting new Medicaid beneficiaries.¹⁵ Low rates, along with the provider disincentives mentioned previously, narrow the pool of acceptable Medicaid enrolled clinicians who meet the needs of young adult patients with complex needs.

This can prolong the in-between period where patients have no preferred provider willing to accept them. If medical emergencies arise, procedures may be performed by clinicians with less understanding of a patient's history or condition, which can be life-threatening.

Workforce Gaps

While many barriers center on reimbursement disincentives or a lack of adult providers interested in accepting young adults with complex care needs, there are also structural challenges within the medical pipeline. Many adult providers have insufficient knowledge, experience, and skills for caring for those with pediatric-onset conditions and disabilities.¹⁶

Among specialists with the knowledge to treat adult patients with pediatric-onset conditions are dually trained internal medicine and pediatrics (med-peds) physicians. Their distinct training within the adult and pediatric system¹⁷ allows them to understand the needs of patients with complex conditions aging into the adult system. Med-peds physicians normally work in multispecialty practices that assess patients with multiple comorbidities.¹⁸

Despite the value and demand of these dually trained specialists, they only make up a small amount of the medical workforce. Med-Peds residency slots only represent approximately 7% of internal medicine positions.¹⁹ And despite interest from medical school graduates in 2023, there were just 1,500 residents in training.²⁰ The residency training is extensive compared to other programs lasting four years, which is the longest training time for primary care medicine.²¹

Despite relatively low numbers of residents, there are positive signs leading to growth in the specialty. The interest of medical graduates continues to rise for residency opportunities for med-peds hospital medicine.²² If these trends continue, young adults with complex care needs transitioning into the adult care environment could have more primary providers trained to understand the complexities of pediatric conditions.

Coordination of Care

For many young adult patients, the change to adult care comes abruptly. While practices prepare patients for the transition in advance, many patients do not have planned healthcare transition processes. Only 23.1% of all young adults with complex care needs and 24% of the same population in Medicaid receive transition services and preparation from healthcare providers.²³ Without proper assistance, the burden is therefore passed on to the patients and caregivers to navigate into the adult system largely ill-catered for them.

Some health systems and payers may provide forms of coordinated care during the transition process. The use of a dedicated team care coordinator has been used to provide this. The coordinator, usually a nurse with understanding of both systems, facilitates communication between pediatric and adult providers and provides direct information to a patient and their family. They also manage transition preparation and scheduling.

The position seeks to address one of the most prevalent challenges for the transition of care, time demand. Without the coordinator, clinicians usually take up the main lead. However, faced with demanding schedules and time constraints, it is difficult to provide the necessary support for families.²⁴ By acting as a direct contact for patients, coordinators lessen provider workload which allows them to focus solely on patient care.

A coordinator has been identified as a key indicator in the smooth transition process for young adult patients.²⁵ In addition, programs without individual staff dedicated to the HCT process showed increased barriers.²⁶ The findings reinforce the importance of assessing coordination methods as an effective solution for pediatric-to-adult continuity of care. Despite the reported effectiveness of these roles, federal programs currently lack strong quality measurements for these services.²⁷ This remains a challenge in assessing the overall effectiveness of certain HCT services.

Coverage Disruptions

Due to the provisions of the Affordable Care Act, many young adults with complex care needs stay on their parent's insurance until the age of 26. Family plans may have strong coverage for the services in a patient's care regimen. As patients turn 26 and transition to a new insurance plan, providers on their care team are out of network. Healthcare coverage may differ in their new plan compared to their parents.

Coverage disruptions also occur for young adults with complex care needs aging out of youth Medicaid programs. More stringent requirements for Adult Medicaid make it more difficult to qualify as an adult. More than four in ten individuals previously covered by CHIP or Medicaid lose coverage as they turn 19.²⁸ Only a small number of individuals who lose this coverage gain private insurance afterward.²⁹ States that have failed to expand Medicaid require even stricter income qualifications for Adult Medicaid.³⁰ The drop-off disproportionately affects the care of young adults with chronic conditions and disabilities who are less likely to afford private or even ACA marketplace coverage if they are kicked off.³¹

Program differences can be confusing for young adults and caregivers due to the complex requirements. Reports show that less than half of general state Managed Care Plans (MCOs) provide assistance for renewals into adult Medicaid³² and even fewer state plans assist in educating families and youth about the differences in coverage between youth and adult Medicaid plans.³³ Additionally, only 4.8% of young adults with complex care needs on Medicaid reported receiving guidance on how to keep insurance moving into the adult system.³⁴

Structured HCT planning is rarely included within Medicaid coverage. In a recent study, the Medicaid and CHIP Payment and Access Commission (MACPAC) found only a small number of MCOs require transitional assistance for beneficiaries.³⁵ Patients without services lack access to care coordinators or case managers who can assist with care navigation and adult Medicaid enrollment. Additionally, the commission found that most Medicaid MCOs do not identify clear HCT processes or monitoring requirements.³⁶ Without structured provisions, beneficiaries may experience wide variations in care outcomes. Unclear processes can create confusion around the services provided within a patient's plans.

Patients who experience coverage changes must search for qualified adult providers in new care plans. Plans may not provide coverage for necessary services routine in their pediatric care regimen, resulting in patients paying out of pocket for much-needed care. Extensive adult plans able to address care needs may require expensive premiums as well. Costs for these expenses, many of which are unaffordable, may force patients to skip care increasing the likelihood of major health emergencies.³⁷ These risks emphasize the importance of early planning before a patient reaches the age of transition.

Mental Health Challenges

Care transition can have major effects on the mental health of young adult patients. They usually develop strong relationships with their care team in the pediatric system. As mentioned, this is the main reason patients value and prefer pediatric providers. Strong medical relationships can ease the stress of intrusive procedures.³⁸

Patients with complex care needs can undergo many intrusive and intense procedures with various complications. For example, young adult hydrocephalus patients may have had over 20 brain surgeries by the time they are 18. Without a qualified neurosurgeon who understands complex hydrocephalus, life-threatening medical errors may occur. The uncertainty that comes with the pediatric-to-adult care transition can exaggerate the high levels of anxiety already present within these patients.³⁹ Transitioning patients and their families need adult providers who can provide the same level of confidence they had in pediatric care.

Additionally, new levels of responsibility required in the adult healthcare system can be overwhelming for young adult patients. The absence of early-planning assistance may make individuals feel unprepared for role shifts.

Health System Response

To address the challenging demands of the pediatric-to-adult healthcare transition, some health systems have established programs to strengthen the continuity of care for patients with complex conditions. Many programs operate similarly to provide coordinated care for patients and families. These forms of assistance can lessen the overall time it takes for patients to find an adult care team that meets their needs. While effective, many patients do not have access to these types of resources.

Children's Alabama's program called the Staging Transition for Every Patient (STEP) assists patients 18 and older with disabilities or complex needs during the transition process. An individualized plan for each patient offers a patient-centered approach during the coordination of care. The program works with the University of Alabama (UAB) Medical Center to place patients with new adult providers. Regardless of insurance, patients can receive educational services and coordination through nurse coordinators in the clinic.⁴⁰

Additionally, the STEP program helps to educate adult providers across Alabama about the medical needs of transitioning youth with disabilities and special healthcare needs.⁴¹ The efforts look to bridge the care gaps widely prevalent in rural and underserved Alabama communities.⁴²

The Children's Hospital of Philadelphia's (CHOP) Adult Care and Transition Team (ACTT) works with young adults and their families to create transition care plans. The incorporation of CHOP and other adult Philadelphia hospitals allows the program to identify adult providers. The program simplifies much of the process by transferring medical records, teaching patients how to navigate new changes in the adult system, and explaining insurance questions.⁴³ This can lessen the burden on patients and providers overall.

Baylor's College of Medicine provides transitional assistance through its Transition Medicine Clinic (TMC). Through the use of licensed medical social workers and trained physicians, patients are provided with long-term care plans, which identify adult providers in their care networks.⁴⁴ Similarly to other transition programs, patients are prepared for their new responsibilities in adult care and receive assistance navigating through insurance changes.⁴⁵

While the programs provide verified benefits to transitioning patients in the form of coordination, education, and staff assistance, quality statistics on the program's outcomes are less prevalent. Structured measurements on the time resources and transition outcomes of each program could reinforce the demonstrated effectiveness that has been cited on an anecdotal level.

Federal Stakeholder Response

Although relatively little action has been taken by the federal government, there have been some steps taken to address challenges for youth transitioning to adult care. In 2005, the Health Resources and Services Administration (HRSA) realized the importance of the issue and partnered with the National Alliance to Advance Adolescent Health to create the National Center for Health Care Transition (Got Transition). The agreement sought to establish strategies and guidance for patients and providers engaged in HCT.

As a result, Got Transition established 6 Core Elements for health systems to follow. The elements are as follows:⁴⁶

1. Healthcare systems should develop and discuss transition and care policies. Policy guidelines are advised to be shared when the patient is between the ages of 12 and 14.
2. There should be mechanisms to identify and track patients 12 and older for them to begin the transition process.
3. At the age of 14, providers should administer a transition readiness assessment to identify needs of the patients.
4. Between the ages of 14 and 18, healthcare systems should develop an individualized healthcare transition plan that will facilitate smooth continuity of care.
5. Patients should undergo the transition of care to an adult provider able to assess their medical needs between the ages of 18 and 21.
6. The transition should be completed.

The processes of many hospital transition programs follow these core elements. However, healthcare systems without programs may vary in adherence. A 2011 analysis by the Children's Hospital of Philadelphia (CHOP) found that providers experience many barriers to following Got Transition's core elements including inadequate levels of support staff and coordinators to implement the core steps.⁴⁷ More recent findings state between 17% and 40% of adolescents are readily prepared for adult transition.⁴⁸ This would suggest the majority of patients lack structured HCT processes that adhere to Got Transition's suggested elements.

More recently, the Medicaid and CHIP Payment and Access Commission (MACPAC) have begun to look into the issue. In March of 2024, the commission put out a short publication looking into Medicaid MCO coverage regarding the continuing of care for young adults with complex care needs. After conducting a state policy scan and literature review, it found that coverage for transitional services was extremely scarce.⁴⁹ Specified transition processes and monitoring were also lacking. The commission has confirmed future analysis on the issue with patients and providers' focus groups.

HHS's Administration for Community Living funded a recent grant that established the Center for Transition to Adult Health Care for Youth with Disabilities. The program seeks to educate HCPs and provide preparatory resources for patients and caregivers during the HCT process. Its role, however, does not provide new guidance on policies affecting the continuity of care.

POLICY SOLUTIONS

1. Funding Medicaid HCT Assistance through MCH Services Block Grants

One of the ways state Medicaid agencies provide coverage and services for children and young adults with complex care needs is through Title V Maternal and Child Health (MCH) Services Block Grants. The program, administered through the Health Resources and Services and Administration (HRSA), gives states flexibility in how they use funding.⁵⁰ The structure works to address health priorities specific to each state's population. In FY2024, state MCH Block Grant Funds totaled \$593.3 million.

The program includes requirements that each state must meet to qualify for funding. States must report back on the effectiveness of the grants every five years. They must also submit annual data like National Outcome Measures, National Performance Measures, and Evidence-informed (or evidence-based) Measures.⁵¹ The reporting ensures overall efficient use of funds and transparency on care outcomes. Additionally, states must use 30% of funds to address issues specific to children and youth with complex care needs (CYSHCN).⁵²

Some states like Massachusetts direct funds to provide technical assistance to Medicaid providers during the transition process, which can lessen the burden of care coordination.⁵³ However, despite these requirements and the overall effectiveness of structured HCT services for teens with complex care needs, most Medicaid programs do not use the grants to address pediatric to adult transition.⁵⁴

To provide stronger assistance for Medicaid beneficiaries during the transition of care, Congress could require states to use the CYSHCN Title V Program funds for HCT services. This could be directed to assistance for providers, educational programs, access to care coordinators, and planning services. By mandating funds for transitional assistance, Title V agencies would be able to better aid the majority of teen beneficiaries with complex care needs who face significant barriers during the continuity of care. The current reporting requirements would also assess the effectiveness of these HCT services, which could help Medicaid agencies evaluate best practices for the program.

2. Expanded Coverage for Medicaid HCT Services

As mentioned previously, the majority of Medicaid MCO contracts that do not assist beneficiaries during the transition period create significant gaps for patients. Without the assistance of case managers or nurse coordinators, the burden is largely left up to providers to coordinate. Limited time and availability create difficulties for providers to adhere to the 6 core elements of transition. Patients and families also struggle to understand eligibility rules for Adult Medicaid qualification with this help.

To eliminate this, State Medicaid programs should establish provisions for young adults with complex needs in MCO contracts that identify transition processes including the use of care coordinators or care managers.

Specified transition processes will establish a clear timeline for patients and providers. Patients will also gain clarity of what services will be covered during the process. Additionally, HCT staff will provide necessary assistance during the adult Medicaid enrollment process. An analysis by Got Transition found that less than half of the state Medicaid MCO contracts they surveyed assisted with redeterminations.⁵⁵ Beneficiaries may lose adult coverage while still being eligible due to the complexity of the process. By mandating assistance through MCO contracts, Medicaid agencies can largely prevent this falloff and create a more efficient process overall.

3. Utilizing Alternative Payment Models During the Transition Process

Of the largest challenges in care transition is the amount of time and resources demanded to facilitate the transition of care. Providers are inadequately reimbursed for the amount of time it takes to prepare documents, educate families, and coordinate with adult providers.

To lessen the burden, CMS should incentivize state Medicaid programs to use 1115 Waivers that utilize alternative forms of payment to adequately reimburse providers during the transition period. This could include specific billing codes for transitional services (like the ICD-10-CM code) or increased reimbursement during the period of transition. Plans could also allow adult and pediatric providers to bill for the same patients during transition. Additionally, payments should be structured around a value-based care (VBC) structure.

Bundled payments and shared savings models would align incentives for different providers to coordinate efficient transitions. A single payment is given to multiple providers involved in a patient's episode of care. In this case, it would involve the pediatric and adult team facilitating the transition. Since the payments are bundled together, providers will share in the savings resulting from providing efficient care during the transition process. As a result, patients receive effective coordination while the providers receive strong payment. Payers could utilize pay-for-performance models that reward providers for meeting different milestones or outcomes in care. Reimbursement agreements would incentivize pediatric providers to facilitate transition to adult care before a certain age.

Small-scale alternative payment models have seen positive results. A 2023 study using select DC Medicaid specialty MCOs assessed the effectiveness of value-based payments during HCT.⁵⁶ Instead of traditional fee-for-service (FFS), pay-for-performance and bundled payments were used to reimbursement providers. Study patients and providers reported mostly positive feedback while the DC Medicaid plan stated strong support for continuing HCT VBPs.

Given these outcomes, utilization of HCT alternative payment structures should be a key solution for Medicaid Agencies moving forward.

4. Interagency Coordinating Committee for Transition within HHS

Many agencies within HHS have direct authority and oversight of the transition of care for young adult patients with complex conditions, including but not limited to HRSA, CDC, and AHRQ. Although there is strong jurisdiction overlap between different agencies, evidence of collaboration remains unclear. Additionally, the Centers for Medicare & Medicaid Services (CMS) have not set any federal requirements on the transition of care for young adults with complex healthcare needs.⁵⁷ Given the scarce amount of federal focus and collaboration, HHS should establish an Interagency Coordinating Committee for Healthcare Transition.

If implemented, the committee would function as a focal point for all initiatives and federal resources invested into HCT policy responses. This approach would not be uncommon. Multiple coordinating committees within HHS focus on issues like aging and underage drinking. The committee would also guide federal agencies on new programs and initiatives which would directly influence the coverage and transition preparation for young adult patients transitioning to adult care.

Strengthened coordination could increase the limited amount of federal quality measurements evaluating the effectiveness of coverage, services, and practices in HCT. New forms of federal data collection provide lawmakers with data that can influence policy. Overall, dedicated HHS staff would accelerate the implementation of new policy solutions that would benefit youth patients transitioning into adult care.

5. Expanding Medicare Funding for Med-Peds Residency

The training requirements for dually trained pediatric-internal medicine (Med-Peds) physicians provide extensive expertise in the care management of adult patients with pediatric-onset conditions during the HCT process. Despite the benefits of these providers, residency opportunities are relatively less compared to other fields. There are between only 75 and 80 med-peds programs within the United States, compared to a significantly larger number of programs for internal medicine and pediatrics.⁵⁸ To satisfy the strong workforce needs of Med-Peds, federal stakeholders must work to expand residency program slots within hospital training programs.

Medicare has a significant influence on the residency opportunities provided at accredited training programs through Graduate Medical Education Payments (GME). The agency represents the largest form of funding for overall training costs.⁵⁹ Despite some benefits of the GME funding structure, there are opportunities for improvement.

GME payments largely fail in addressing emerging workforce issues like med-peds demands. Medicare-supported positions are capped at each program. Hospitals looking to create new programs do not receive payment for startup costs as well.⁶⁰ These can disincentivize hospitals looking to expand new residency opportunities. To increase the amount of available residency opportunities, Medicare should expand GME payments to assist hospitals with establishing new med-peds programs. They could also provide funding for current med-peds programs to expand their residency size.

Medicaid programs, another avenue of GME funding, should also improve investments toward new med-peds programs. States with larger populations of youth patients with complex healthcare needs would benefit specifically from this change. As residency opportunities increase, there will be more physicians able to assess young adults with pediatric-onset conditions as they transition into adult care.

CONCLUSION

In order to promote the possibility for all youth to successfully grow into adulthood, we must be willing to provide solutions for Children and Youth with Special Healthcare Needs to experience safe and effective opportunities to access the healthcare they need to thrive as adults. Without guidance and assistance; patients, families and caregivers will continue to bear the brunt of the burdens associated with healthcare transition. The absence of coordination and assistance for young adults with complex care needs will continue to cause negative outcomes and major health emergencies within the American healthcare system. Additional avenues for support and assistance will help providers and patients adhere to the core principles of transition.

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