

# Strengthening the Adult Primary Care Workforce to Support Young Adults with Medical Complexity Transitioning to Adult Health Care

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THE NATIONAL ALLIANCE  
TO ADVANCE ADOLESCENT HEALTH



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## Questions

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# EXECUTIVE SUMMARY

## Overview

Young adults with medical complexity (YAMC) are an often-overlooked high need patient population for whom the adult health care system is not well-prepared to receive. Depending on the definition, it is estimated that these individuals represent between 1.4% and 11% of the young adult population. Those with the greatest need experience a combination of chronic conditions, functional limitations, and often co-occurring intellectual and developmental disability that result in high health care utilization, costs, and technology assistance needs. When YAMC age out of the pediatric system, their care often shifts from interdisciplinary care teams at children's hospitals to individual adult primary care providers (PCPs).

PCPs can play a critical role in the management of YAMC's unique health care and psychosocial needs, and many already possess the foundational competencies and skills needed to provide this patient population with high-quality primary care. Yet organization and systems-level factors present barriers to care transitions from the pediatric to adult health care system for YAMC. Patients, their families, and pediatric providers consistently report difficulty in finding adult PCPs for YAMC. Adult PCPs lack the enabling services and infrastructure to care for YAMC in the ways that are available in pediatric complex care and needed to assure effective coordination and care. The lack of a care system has a major impact on the quality of lives of these young adults and their families.

To address these issues, The National Alliance to Advance Adolescent Health/Got Transition and the George Washington University Fitzhugh Mullan Institute for Health Workforce Equity, with the support of the federal Maternal and Child Health Bureau, established a national Advisory Committee on *Strengthening the Adult Primary Care Workforce to Support Young Adults with Medical Complexity Transitioning to Adult Health Care* (the Advisory Committee) to develop recommendations to promote an increased supply and distribution of well-prepared adult PCPs with systems supports to care for this population.

The resulting ten recommendations are targeted to the following five areas of critical importance that guided the Advisory Committee's work throughout the fall and winter of 2022-23:

- 1) Preparing the future health workforce through education and training;
- 2) Providing additional supports for the current primary care workforce;
- 3) Supportive payment policy;
- 4) Research on key needs and issues impacting on care of YAMC; and
- 5) Coalition-building for implementation and sustainability.

Though these recommendations were developed in response to the needs of the YAMC population, the Advisory Committee asserts that their adoption would promote high-quality primary care for other medically vulnerable populations, as well.

## Recommendations

### ***Prepare the Future Health Workforce to Care for Young Adults with Medical Complexity (YAMC)***

**#1:** Require medical, nurse practitioner (NP), and physician assistant (PA) students and residents in family medicine and internal medicine to have a minimum exposure to the needs of complex patients with childhood-onset medical conditions through curriculum and experiential learning opportunities.

**#2:** Establish fellowships for adult PCPs, NPs, and PAs focused on YAMC to build a cadre of leaders in care, research, and policy.

### ***Support the Current Adult Primary Care Workforce to Care for YAMC***

**#3:** Build on existing training infrastructure supported by the federal government to train and provide technical assistance to existing and future PCPs related to care for YAMC.

**#4:** Create state or regional Centers of Excellence for the care of YAMC to facilitate knowledge sharing among pediatric and adult PCPs and specialists providing care for YAMC.

### ***Payment Policy to Support Adult PCPs in Serving YAMC***

**#5:** Establish payment arrangements that incentivize and support PCPs in providing care to meet the care delivery needs of YAMC.

**#6:** Embed care coordination and other infrastructure supports within all payment models for adult PCPs serving YAMC.

**#7:** CMS should use its Innovation (CMMI) Center funding and state Medicaid agencies should use their existing authorities to support payment and delivery models that promote safe, effective, and integrated adult primary care for YAMC.

### ***Support for Research to Improve Care of YAMC***

**#8:** Increase federal research support to build the evidence base for primary care delivery and related workforce strategies for YAMC, including through the establishment or enhancement of an existing research center.

**#9:** Establish a Pediatric and Adult Complex Care Research Network to improve continuity of care between pediatric and adult care and to efficiently expand and assess adult primary care capacity to serve the growing population of YAMC.

### ***Build a Coalition of Interested Organizations to Support Expanded Adult Primary Care Capacity for YAMC***

**#10:** Convene a series of meetings with key stakeholders interested in improving adult primary care services available to YAMC to present findings and recommendations from this report and to build a coalition to support implementation and follow up activities.



# INTRODUCTION

## The Problem

Advances in science, technology, and pediatric medical care have enabled an increasing number of children with complex medical conditions to live into adulthood (Cohen & Patel, 2014). This includes young adults with such conditions as cerebral palsy, cystic fibrosis, spina bifida, blood diseases, and mobility disorders. Care delivery for this growing population of young adults with medical complexity (YAMC), who experience a combination of chronic conditions, functional limitations, often including co-occurring intellectual and developmental disability, and high health care utilization and technology assistance needs are now entering adulthood and needing to move from the pediatric to adult health care system (see Box 1 for a patient example).

### **Box 1. Young Adult with Medical Complexity: Maddie and Dr. Berkowitz**

Maddie was diagnosed with a rare, progressive brain disorder as a baby. Her complex medical needs and difficult experience with the transition from the pediatric to adult health care system were described by her physician and mother in a family partnerships article in *Pediatrics*: “At the time of Maddie’s (health care) transition, her medical history included 30 past and current medical problems, 15 different surgical procedures, 48 medications, 15 pieces of medical equipment, and 15 different subspecialists.”

This transition process was fraught with challenges, according to Maddie’s pediatric complex care physician. “Not only is finding a new primary care clinician extremely difficult, coordinating transition for all other specialists, therapies, and routine procedures is as well. Expecting families to tackle all of this on their own is neither realistic nor patient centered. At the same time, the amount of time and energy it takes for a clinician to do this, even with the assistance of care coordinators, can be daunting.” *Excerpted from Berkowitz & Lang (2020) with the authors’ permission.*

When YAMC do transition from the pediatric to adult U.S. health care system, they are often ill-prepared as is the adult system to receive them. The adult primary care providers (PCPs) lack the infrastructure to support the required care delivery for this high-need population. Perhaps not surprisingly then, YAMC and their families have described the care they receive after transitioning to the adult health care system as inconsistent with fewer resources and more difficult to navigate compared to the pediatric setting (Zhou et al., 2016). Advocacy efforts in response to the growing number of children with medical complexity (CMC) have driven strategic investments in the pediatric health care system that have helped to support the infrastructure needed to facilitate interdisciplinary complex care clinics (Cohen et al., 2018; Berry & Feudtner, 2023). Yet, similar investments have not been prioritized for YAMC moving into the adult health care system, which remains largely siloed, with care coordination, mental and behavioral health services, and linkages to social supports often absent. Some have likened the transition to the adult health care system for YAMC as a “care cliff.”

In the pediatric health care system, care for CMC is often provided by interdisciplinary care teams providing both primary and specialty care services in the children’s hospital setting. In the adult health care system, comparable arrangements are generally unavailable, placing a much greater burden on the YAMC, their family, and the adult PCP to identify and arrange for needed services and care coordination. It is recognized that care for YAMC in the adult health care system typically begins with establishing primary care, defined to include physicians, nurse practitioners, and physician assistants. Their roles in complex care can include health promotion and education, preventive services, care coordination, and longitudinal care continuity working closely with needed specialists,

considering patients' social determinants of health and addressing their psychosocial needs, helping patients make informed decisions, and serving as a patient's medical home in an otherwise fragmented system (Cohen et al., 2018; National Academies of Sciences, Engineering, and Medicine, 2021; Okumura et al., 2010; Potosky et al., 2011). Further, for YAMC in rural areas, PCPs may be the only proximate source of health care (Phillips et al., 2022).

Despite experts' recommendations that high-quality primary care (Box 2) is central to the management of complex conditions, patients, families, and pediatric providers consistently report difficulty in finding adult providers for YAMC (Roy et al., 2022; White & Cooley, 2018). These challenges are rooted in many factors, including a general shortage and maldistribution of adult PCPs, inadequate preparation of adult providers to care for YAMC contributing to provider discomfort in doing so, and insufficient practice environment accommodations (White & Cooley, 2018). Above all, adult PCPs lack the enabling policies and infrastructure (e.g., adequate payment, care coordination support, consultative services) to care for YAMC in the ways that are available in pediatric complex care.

Policies and programs targeting the organization and systems levels are needed to ensure every YAMC has access to a person-centered adult health care system with a PCP who is prepared and supported to meet their needs as they transition to adult care.

### **Box 2. Defining High-Quality Primary Care**

The National Academies of Sciences, Engineering, and Medicine's Committee on Implementing High-Quality Primary Care defines high-quality primary care as the provision of whole-person, integrated, accessible, and equitable health care by interprofessional teams who are accountable for addressing the majority of an individual's health and wellness needs across settings and through sustained relationships with patients, families, and communities (National Academies of Sciences, Engineering, and Medicine, 2021). This definition espouses many of the core concepts integral to successful care delivery for YAMC.

## What is the Purpose of this Report, and How is it Organized?

The National Alliance to Advance Adolescent Health/GoT Transition (NA) and the George Washington University Fitzhugh Mullan Institute for Health Workforce Equity (GW), with the support of the federal Maternal and Child Health Bureau (MCHB), established a national Advisory Committee on *Strengthening the Adult Primary Care Workforce to Support Young Adults with Medical Complexity Transitioning to Adult Health Care* (the Advisory Committee) to develop recommendations to promote an increased supply and distribution of well-prepared adult PCPs to care for YAMC transitioning into adult care. Sections 1-3 of this report provide an overview of the YAMC population and the current complex care landscape, including health workforce and financing considerations. Section 4 presents recommendations to strengthen the primary care workforce for YAMC targeted to the areas of future workforce preparation, supporting the existing primary care workforce, research, payment and financing, and coalition-building.

## How were the Recommendations Developed?

In 2022, NA and GW convened the Advisory Committee to discuss the critical health care system and workforce issues affecting YAMC transitioning to the adult care system and develop recommendations to strengthen the adult primary care workforce to meet this population's needs. The Advisory Committee was carefully selected to represent a broad array of expertise. Members included pediatric and adult clinicians with

experience caring for this population, researchers, payers, disability organizations, and patients and family members with lived experience, as well as federal representatives serving in an ex-officio role (Appendix A). The Advisory Committee was convened five times between the fall of 2022 and winter of 2023. Prior to the first convening, key informant interviews were conducted with over 25 clinical, family, and payer experts to identify challenges and opportunities for improving the adult primary care workforce. Interviews were analyzed to identify dominant themes, which guided the organization of the Advisory Committee meetings:

- Meeting 1 (September, 2022): Defining the YAMC population;
- Meeting 2 (October, 2022): Approaches to care delivery for medically complex populations;
- Meeting 3 (November, 2022): Strategies to increase and expand the PCP workforce;
- Meeting 4 (December, 2022): Options for financing and payment in complex care; and
- Meeting 5 (January, 2023): Review of draft recommendations.

Meetings were facilitated by health workforce researchers and health care transition (HCT) experts and supplemented by theme-specific presentations. Surveys were also distributed to Advisory Committee members to elicit additional feedback. Survey results, transcripts, and notes from the Committee meetings were analyzed and synthesized by four members of the project team to inform draft recommendations. Though this project did not aim to establish a formal consensus, Committee members were provided the opportunity to provide feedback on draft recommendations (Meeting 5), which the project team incorporated into the final set of recommendations. To ensure recommendations aligned with relevant existing calls for action, a review of published literature was conducted to identify expert-informed or consensus recommendations in related areas, including complex care, primary care, and HCT.

## BACKGROUND

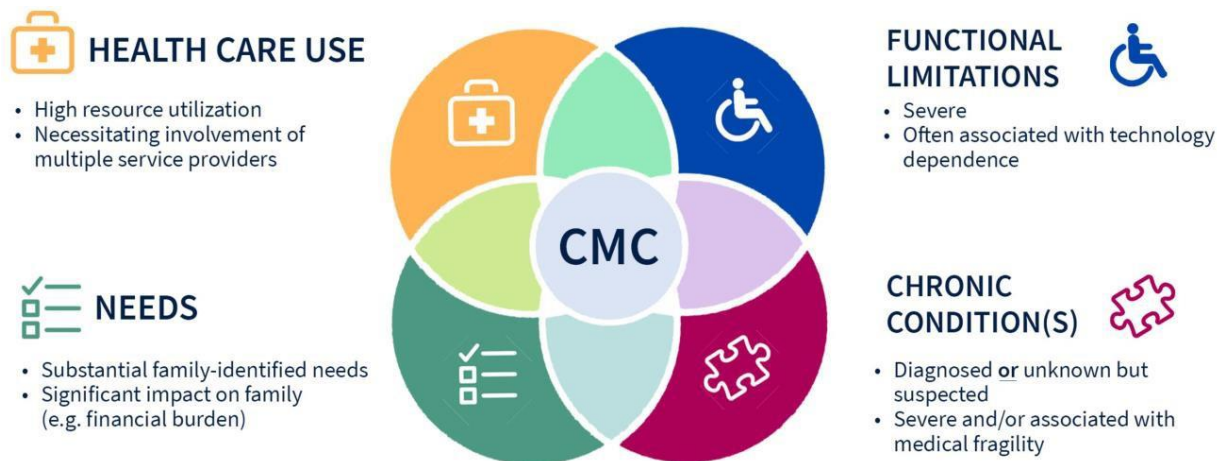
### Young Adults with Medical Complexity (YAMC)

#### *Defining and Estimating the Size of the Population*

Defining the YAMC population is an important initial step in designing health care policies and programs targeted to meet patients' and families' needs. This is particularly true in workforce planning, where establishing prevalence estimates and patient population characteristics for a given population is integral to determining the needed supply, distribution, and competencies. According to the American Academy of Pediatrics (AAP), CMC – many of whom now survive into young adulthood – “have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology” (Kuo et al., 2016). An adapted version of these criteria was conceptualized by Cohen and colleagues in a definitional framework for CMC (Figure 1).



**Figure 1. Children with Medical Complexity: A Definitional Framework**



Source: Adapted from Cohen et al., 2011

While conceptual approaches to defining the CMC population are helpful in establishing general criteria, operationalizing the definitions is necessary to establish prevalence rates. Operational definitions of medical complexity among children, based on a variety of coding criteria and algorithms, are often used and can provide helpful estimates of population prevalence, but these definitions may be limited in their specificity as administrative datasets are generally not designed to collect information on needs and functional limitations. Estimates of population prevalence using these sources range from 0.7% to 11% (Leyenaar et al., 2022). In 2020, the Children’s Hospital Association developed an expert recommendation for the Centers for Medicare and Medicaid Services (CMS) to provide guidance for operationalizing the agency’s definition of “children with complex medical conditions” as part of the Advancing Care for Exceptional (ACE) Kids Act (Children’s Hospital Association, 2020; CMS, 2022). The guidance recommended the use of claims data with a modified Complex Chronic Condition classification system to identify children with three or more complex chronic conditions who are technology dependent (also known as the CCC3+ algorithm) plus the addition of a mental health condition (Feudtner et al., 2014; Zima et al., 2020). Using this operational definition (Table 1), the prevalence of CMC as defined by the ACE Kids Act was estimated at 1.4% (Children’s Hospital Association, 2020).

There are no analogous algorithms to define medical complexity in young adults. As a result, there are no national estimates of the size of the young adult population, ages 18 through 26, with complex medical conditions.

**Table 1. Children’s Hospital Association’s Operational Definition of Children with Medical Complexity Based on a Modified Complex Chronic Condition Classification System Algorithm**

<b>Complex Chronic Condition (CCC)</b>	<b>≥ 3 Body Systems (CCC3+)</b>	<b>Mental Health Disorder</b>
Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center. (Feudtner et al., 2014)	Among those meeting conservative criteria, ICD 9/10 codes for ≥3 CCC-CS body systems (e.g., respiratory, neuromuscular) and/or technology dependence (Leyenaar et al., 2022)	As defined by the Child and Adolescent Mental Health Disorders Classification System (Zima et al., 2020)
<b>Prevalence</b> (Children’s Hospital Association, 2020; Leyenaar et al., 2022)		
<b>5.7%</b>	<b>0.7%</b>	<b>1.4%</b>

## ADVISORY COMMITTEE CONCLUSION

### Definition of YAMC

Although there is no widely accepted definition for YAMC, for the purposes of developing this report and set of recommendations, the Committee relied on the CCC3+ algorithm with the modification to include mental health conditions as an additional complex care condition. This algorithm estimates medical complexity among children at 1.4%, and thus the Committee assumes prevalence rates among young adults aged 18-26 may be somewhat similar.

The Committee chose to define YAMC based on the CCC3+ algorithm for two main reasons: 1) the definition is consistent with current criteria set forth in the ACE Kids Act of 2019 and mandated in CMS implementation guidance; and 2) by targeting workforce recommendations to meet the needs of the most medically complex individuals, the “floor” of care access and delivery is raised for all, whereas defining medical complexity more broadly may not serve to meet the needs of the most medically complex young adults. The Committee acknowledges that the 1.4% prevalence represents a narrow segment of the patient population, but also asserts that there is an urgent need to strengthen care delivery and support for this group given their high health care utilization and costs and documented system deficiencies that have disproportionate negative consequences for this medically vulnerable population (Burns et al., 2010; Cohen et al., 2012; Simon et al., 2010).

### *Characteristics of the YAMC Population*

Advancements in modern medicine have resulted in increased numbers of children with complex chronic conditions surviving into adulthood. Even the conservative estimate that 1.4% of young adults have complex medical care needs represents nearly 500,000 individuals aged 18-26, based on analysis of 2020 Census data conducted by the authors of this report. Some of the characteristics of this patient population, such as the breadth and intensity of their conditions and resultant substantial care coordination needs, are consistent with the pediatric complex care population. Yet, developmental, life stage, and other factors distinguish the YAMC patient population and warrant additional attention, as described below in Table 2. Though, as was mentioned in the previous section, this population has not been well studied or defined (Li et al., 2022).

**Table 2. Distinguishing Characteristics of YAMC**

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**Psychosocial development** – Identity formation, peer belonging, resilience, and self-efficacy and determination are integral facets in young adults’ psychosocial development, yet poor psychosocial functioning is a documented barrier to HCT for YAMC (Gray et al., 2018; John et al., 2022; Li et al., 2022; White & Cooley, 2018).

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**Heterogeneity of etiology** – YAMC experience a broad range of rare medical conditions, with and without mental health and development conditions and associated functional limits (Jenkins et al., 2022), though some (such as cystic fibrosis, spina bifida, and cerebral palsy) are frequently mentioned in the literature (Berens & Peacock, 2015; Boggs et al., 2021).

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**Increasing complexity** – As YAMC age, they may accumulate additional medical conditions, thus increasing in complexity (White & Cooley, 2018).

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**Sexual and reproductive health** – Just as they are among their peers, issues related to reproductive and sexual health and contraceptive use are salient needs among YAMC population (Rosen et al., 2003).

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**Mental and behavioral health** – Health risk behaviors develop during this period that may lead to preventable morbidity and mortality; Committee experts note a high degree of behavioral health complexity among YAMC; there is a high prevalence of mental health conditions (also, a period when many mental health conditions emerge) (Kessler et al., 2005) and increased exposure to abuse and neglect and bullying and traumatization (Thompson-Lastad et al., 2017).

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**Decision-making shifts** – At age 18, when YAMC are considered adults, unless decision-making supports have been put in place, the decision-making roles of parents/caregivers shifts to the patient; parents and primary caregivers for YAMC are aging and may be unable to play as active a role in their care, compared to caregivers of children.

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**Diminished adherence to care** – Evidence confirms decreased adherence to medications and follow-up care among YAMC (Vaks et al., 2016).

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**Health insurance shifts** – YAMC lose their childhood eligibility status between ages 19 and 25, under public and private coverage; corresponding shifts also happen with changing health plans and participating providers; YAMC are disproportionately covered by Medicaid (Jenkins et al., 2022).

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**Loss of Other Childhood Public Program Supports** – YAMC are aging out of special education services, supplemental security income (SSI) during the age 18 redetermination process (Hemmeter & Gilby, 2009), and State Title V maternal and child health programs and services. Adult public program services, if available, have more restrictive eligibility criteria than criteria used for children. Also, YAMC, if able, are moving into employment, post-secondary education, and independent living arrangements.

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## Complex Care Delivery

### *Pediatric and Adult Complex Care Models*

Models of care for the populations of pediatric and adult patients with complex medical needs differ in many ways (e.g., location, payment system, care team staff and staff configuration, services offered, and target population) and are based on multiple factors (e.g., local needs, leadership expertise, patient taxonomies, target population preferences, and financing and institutional support) (National Governors Association, 2017; Long et al., 2017; McCarthy et al., 2015; Pordes et al., 2018). This variation reflects the current lack of consensus in and support for what constitutes best practice. However, within each population, efforts have been made to classify broad approaches to complex care delivery. Models for the pediatric (Box 3) and adult complex care population (Box 4) have been classified by Pordes and colleagues (2018) and the National Academy of Medicine (NAM) (Long et al., 2017), respectively. It is unclear from the adult complex care models the extent to which they are designed to serve a young adult population or if they are intended mostly for an older adult population, but many exemplar models are targeted to Medicare beneficiaries (Long et al., 2017; Shah et al., 2019). The models of care presented in this report are not intended to reflect the universe of complex care models, but rather to convey broad approaches to care delivery. As implemented, there is wide heterogeneity in care delivery models, which may differ across health systems and practice sites.

#### **Box 3. Models of Pediatric Complex Care (Pordes et al., 2018)**

1. **Primary care-centered models:** Community or tertiary care-based medical homes that typically provide preventive and sick care, as well as anticipatory guidance for acute care needs. Emphasis on services that are continuous, coordinated, compassionate and culturally appropriate, with primary care at the center.
2. **Consultative or co-management-centered models:** Ambulatory or combined inpatient and ambulatory model in which complex care or subspecialty programs provide consultation and care coordination supports to community providers, often PCPs. Emphasis is on care coordination, goal directed co-management of medical issues, and serving as a bridge between the tertiary care center and the community.
3. **Episode-based models:** Location-specific or time-limited services for acute or transition care medical management (e.g., hospital inpatient service or transitional care homes with complex care capacity).

Identification of complex models of care for young adults transitioning from the pediatric to adult system is largely absent from the published literature and complex care program listings, yet practice examples do exist. For example, in 2005, the Transition Medicine Clinic was established in Houston under the auspices of the Baylor College of Medicine's adult clinical practice through a partnership with Texas Children's Hospital. Based on the patient-centered medical home model, the clinic provides pediatric-to-adult transitional care and primary care to YAMC. It affords patients extended clinic visit times and access to a full-time social worker, resources that require a combination of grant, philanthropic donation, and in-kind support (Berens & Peacock, 2015). In Indiana, the Center for Youth and Adults with Conditions of Childhood is an example of a statewide consultation and care coordination model for YAMC, working in partnership with community-based adult primary care practices. Affiliated with the Indiana University Health system and embedded in a federally qualified health center (FQHC), it offers interdisciplinary care teams, comprehensive assessments, medical summaries, and a nurse to provide free care coordination to adult primary care practices serving complex patients following the transition from pediatric care. The program has been supported by Indiana Title V block grant dollars, state Medicaid funding, and funding from The Coronavirus Aid, Relief, and Economic Security (CARES) Act. (M. Ciccarelli, personal communication, March 3, 2023).

#### **Box 4. Models of Adult Complex Care (Long et al., 2017)**

1. Enhanced primary care: Primary care-based programs provide interdisciplinary primary care, care and case management, and chronic disease self-management.
2. Transitional care: Models focus on episodic care during transitions between the hospital and next care site.
3. Integrated care: Cross-disciplinary models integrate features of medical, social, and behavioral health services.

While variation exists across pediatric and adult complex care models based on multiple factors, commonalities exist in the key features that contribute to their success. They have been summarized by NAM and include specific content attributes (patient assessment and targeting of those most likely to benefit, evidence-based and patient/family-engaged care planning, care matched to patient goals and needs, strong care coordination and team communications, proactive patient health monitoring, and care continuity across time and settings) and delivery features (multidisciplinary care teams, care coordination and patient outreach, 24/7 provider availability, clinician feedback and data for remote patient monitoring, medication management, linkage to social services, and prompt follow-up and implementation of discharge protocols after hospital stays) (Long et al., 2017).

In 2022, NA conducted a survey from a convenience sample of providers at complex care clinics (pediatric/adult/both) to understand program characteristics, including services offered. Respondents (n=38) indicated that they offered many of the delivery features identified by NAM in successful care models, with two-thirds or more providing: community and peer support services (95%); care planning/medical summaries (89%); behavioral health specialists (76%); adult medical providers (74%); legal resources (71%); assistance in retaining or finding insurance (68%); and/or 24/7 phone access for families (66%). All respondents indicated that their clinic offered telehealth services. Consultation for PCPs and pediatric and adult inpatient hospitalizations, however, were provided by a minority of respondents (34% (pediatric), 29% (adult), and 13% (both)). The vast majority offered training to medical residents and students. When asked about turning away patients with medical complexity to due to capacity limits, 47% of adult complex care providers responded yes, compared to 26% of pediatric complex care providers.

The array of services embedded in successful complex care models necessitates multidisciplinary care teams committed to strong, culturally responsive patient and family-centered care. Care teams often include PCPs,

medical subspecialists, nurses, social workers, care manager/coordinators, patient navigators, and behavioral health specialists (National Governors Association, 2017; Long et al., 2017). The unifying role in this network of practitioners is often the PCP, who works closely with the YAMC and family to oversee their care and link to other health professionals. This is especially true of some of the common complex care delivery models authorized by CMS, including the Patient-Centered Medical Home, Community Health Teams, and Health Homes (National Governors Association, 2017).

Determining the best or most appropriate model of care for YAMC transitioning to the adult health care system was beyond the scope of this project. However, care delivery models have important implications for workforce planning, as different segments of the complex care population require different services and workforce competencies and configurations.

**ADVISORY COMMITTEE CONCLUSION:  
Care Delivery Models for YAMC**

There is no best “one-size fits all” care delivery model for this population, nor should there be. The “best” model of care will be one that is designed to meet the needs of the young adults and families and is tailored to the regional context and local capacity, building on available resources like tertiary care consultation, telehealth capacities, and care coordination supports. Models can be designed as either primary care medical homes (based in tertiary care or community settings) or using a consultative/co-management approach between PCPs and subspecialty providers.

Importantly, successful care models targeted to the YAMC population must factor the distinctive needs and characteristics of these patients and their families (Table 2) into their content, workforce, and delivery features. Among the many features these models include are active engagement of patients and families, incorporation of behavioral and reproductive health specialists, extended office and home visits, familiarity with durable medical equipment and authorization processes, intensive care coordination, assistance with securing adult public program services, legal expertise and decision-making supports, and readily available pediatric and adult specialty consultation via telehealth.

## Health Care System Challenges for YAMC

As YAMC age out of the pediatric system, their care shifts to a health care system ill-equipped to meet their needs. This lack of systems preparedness is rooted in structural factors that impede care delivery, from poor integration and coordination between the pediatric and adult health care systems resulting in challenges transitioning between the two to dominant payment models that fail to incentivize the integrated, interprofessional, personalized care YAMC need. Ultimately, access to high quality primary care for all YAMC is contingent upon having the workforce needed to deliver it, yet a lack of supportive policies, training, and infrastructure pose as challenges to maximizing the role of PCPs in YAMC care delivery.

### *Health Care Transition from the Pediatric to Adult Care System*

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, in the clinical report, *Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home* (White & Cooley, 2018), recommend a structured HCT process from pediatric to adult health care, starting in early adolescence and continuing into young adulthood. It is called the Six Core Elements of Health Care Transition™, developed by NA’s Got Transition. The Delineation of Health Care Transition Activities and Tools (Appendix B) displays how the customizable Six Core Elements are structured for HCT planning, transfer, and integration into



adult care. Positive outcomes, including reductions in morbidity and hospitalizations and improvements in patient/family experience, adherence to treatment, and timely use of adult ambulatory care result when youth with special health care needs receive a structured HCT process (Schmidt et al., 2020).

The clinical report recommends that when pediatric practices plan for transfer to adult care, they should start with the transfer to adult PCPs who can assist in locating and coordinating adult subspecialty, behavioral, and other needed clinical and community-based support services. In addition, the clinical report recognizes the critical interplay required between pediatric and adult clinicians, especially for YAMC.

Despite the evidence on the importance of a planned HCT from pediatric to adult care in patient outcomes and the development of professional guidance, the transition between the pediatric and adult health care systems represents a challenging – and even traumatic – period for patients, their families, and health care providers (Berkowitz & Lang, 2020; Davies et al., 2011; Zhou et al., 2016). Four out of five youth with special health care needs (a group which includes but is broader than CMC) are not receiving needed HCT preparation from their health care providers (Data Resource Center for Child and Adolescent Health, n.d.). Further, continued reliance on children’s hospitals with complex care services for YAMC underscores the challenges that pediatric systems face in transitioning this population to the adult system of care (Berens & Peacock, 2015; Jenkins et al., 2022).

Numerous barriers to successful HCT for youth and young adults with special health care needs have been reported in the literature. These barriers operate at the individual patient, family member, pediatric and adult provider levels and the system level, as shown in Table 3. Exacerbating these barriers is an absence of organized state or regional adult primary care complex care initiatives for the growing population of YAMC aging out of the pediatric complex care system.

**Table 3. Barriers to Transitioning from the Pediatric to Adult Health Care System**

(Berkowitz & Lang, 2020; HIS Markit, 2021; Loeb et al., 2016; Okumura et al., 2010; White & Cooley, 2018; Zhou et al., 2016)

Patient/Family Barriers	Pediatric/Adult Provider Barriers	Organizational/Systems Barriers
Fear and anxiety of new system and providers Negative beliefs about or attitudes towards adult health care Difficulties leaving the familiarity of the pediatric system Gaps in knowledge of their condition and self-care skills Problems with medication and follow-up adherence Heavy reliance on parental involvement Complicated psychosocial and developmental functioning	Lack of training in HCT and childhood-onset conditions Adult provider difficulty meeting psychosocial needs of patients and caring for patients reliant on caregivers Unfamiliarity with resources for patient population Communication gaps between pediatric and adult providers Lack of preparation for transition on pediatric and adult sides Difficulty of pediatric provider to relinquish care	General shortage of PCPs Limited availability of adult complex care centers with specialized knowledge of YAMC Inadequate financial incentives for HCT, care coordination, etc. Loss of insurance coverage/high rates of Medicaid coverage Lack of support staff and care coordination services Administrative constraints and unrealistic provider productivity expectations Fragmentation of adult health care system; mental health and social services are especially poorly integrated

### *Insufficient Financing and Payment*

Current financing and payment structures in the US health care system represent major barriers to expanding and strengthening care delivery for YAMC, especially primary care. Committee members and outside experts note an inherent mismatch between dominant payment policies and the approaches that are needed to incentivize high-quality primary care for YAMC. This gap is rooted in multiple factors (Long et al., 2017).

**Low Medicaid reimbursement rates:** Medicaid serves a disproportionate share of YAMC. Exact estimates are unavailable but have ranged from 44% to more than 80% (with the remainder covered by a mix of commercial insurance or Medicare, or uninsured) (Berens & Peacock, 2015; Jenkins et al., 2022). Low Medicaid reimbursement rates for primary care, which are far below those for Medicare (Zuckerman et al., 2021) and commercial insurance (Mann & Striar, 2022), have been reported by providers as a deterrent to providing care YAMC patients (Berens & Peacock, 2015) and primary care more broadly (Vichare et al., 2022). Further, Medicaid reimbursement is a health equity issue. Since Black and Latino individuals comprise a greater proportion of Medicaid beneficiaries compared to their share of the general population (“Health Insurance Coverage Type”, 2021), these subsets of the YAMC population and the providers who care for them disproportionately experience the negative effects of low reimbursement rates on access to care.

**Fee-for-service (FFS) payment methods:** The dominant health care payment method in the US remains FFS, which reimburses providers and organizations for discrete services billed, rather than the coordination of care and the integration with social services. This payment method is to the detriment of YAMC and their providers, as complex care management is not easily separated into individual units for reimbursement and ideally necessitates collaboration among interprofessional teams across systems of care. As one adult complex care physician noted in a key informant interview, “There is an order of magnitude difference in the workload needed to provide comprehensive primary care for complex care patients compared to others with chronic conditions. I was able to care for 100 complex care patients in my full-time position, but it was not financially sustainable for the institution to continue to support this type of practice.”

**Uncompensated care:** Relatedly, FFS methods do not consistently recognize or allow for the billing of services and supports that are inextricably linked to YAMC care delivery, including the non-face-to-face time spent coordinating transitional care and other ongoing service needs, lengthier home and office visits, preparation of current medical summaries and emergency care plans, time spent on prior authorization requests and finding in-network specialty care and ancillary services, and consultation with specialists, to mention a few. (Loeb et al., 2016; Long et al., 2017; McManus et al., 2022; Szalda et al., 2015). Importantly, Committee members emphasized that high-quality care for individuals with medical complexity requires extra time, staffing, and accessibility accommodations to work with patients to build relationships and understand and address their unique needs.

Value-based and alternative payment models represent a more appropriately aligned payment approach for YAMC care delivery (Blumenthal et al., 2016; Long et al., 2017; National Academies of Sciences, Engineering, and Medicine, 2021). As opposed to FFS models, they can be used to finance needed infrastructure and compensate providers based on the quality and value of care delivered or by providing “global payments” that reimburse for the spectrum of covered services for a specific population. Part of the appeal of these payment models is the flexibility they offer for providing care from an integrated, interprofessional care team (National Academies of Sciences, Engineering, and Medicine, 2021). Although multiple Medicaid authorities exist to support alternative or value-based payment models (National Governors Association, 2017; Fitton & Comeau, 2022), few states or managed care organizations have invested in their use for the YAMC population.

**Defining value:** Payments predicated on the value or quality of care necessitate defining the relevant outcomes by which care delivery should be assessed. Yet, for the YAMC population, these outcomes have not been defined. Further, conventional quality indicators like emergency room visits and hospital readmissions may be

inappropriate for the most medically complex patients, for whom frequent interaction with specialty, emergency, and inpatient care is – to some extent at least – inherent in the management of their medical care. Committee members noted that quality outcomes that may be most salient for the YAMC population, such as patient and family member quality of life, are not currently prioritized in value-based payment algorithms. Nonetheless, demonstrating the value of service delivery designs is integral to their viability and expansion.

**Defining the eligible population:** In health care financing, especially more advanced and flexible models that are more appropriate for complex care, defining the patient population is critical. Yet, as mentioned previously, there is no standard definition for YAMC. While the population has greater needs and fragility than the general population that require a higher intensity and volume of services, the heterogeneity of YAMC make rate-setting for the population and determining their eligibility for global payments a challenge.

In sum, financing is essential for the requisite infrastructure to facilitate high-quality primary care for YAMC. Financing strategies like Medicaid administrative claiming, infrastructure investments using alternative payment methods, and grants administered by the CMS Innovation Center exist for costs associated with program development and administration, care coordination services, health information technology, and training. However, they are seldom taken advantage of and the latter grant options are often time-limited, discretionary, and/or provide only partial funding.

**ADVISORY COMMITTEE CONCLUSION:  
Financing and Payment**

Supportive financing and payment policies are critical to the advancement of an adult health care system capable of delivering high-quality primary care to all YAMC. Current payment policies create a barrier to providing YAMC with the integrated, interprofessional, high-touch and personalized care they need. Further, grants and one-time funding – while valuable – can facilitate innovation but do not provide the sustainable financing that is needed to implement and support ongoing care delivery for the YAMC population. Enhancing and expanding high-quality primary care for YAMC will be dependent on securing hardwired funding for workforce education and training, clinical support staff, and enhanced PCP payments that reflect the reality of YAMC care delivery, health care facility accommodations, and broader health systems infrastructure improvements to facilitate care coordination and timely exchange of health information.

*Adult Primary Care Workforce Challenges*

Ultimately, access to high quality primary care for all YAMC is contingent upon having the workforce needed to deliver it. PCPs represent both an entry point to and hub for the health care system and play a central role in successful complex care delivery models. Yet, for YAMC, a major impediment to accessing quality care in the adult health care system is an insufficient supply, distribution, and capacity of PCPs who are available and supported to provide their care. First, there is a growing shortage of PCPs in the United States that permeates the field (IHS Markit, 2021), with negative implications for all patient populations, and especially the most medically vulnerable. Evidence suggests that increasing the number of PCPs alone will not go far enough to ensure primary care needs of YAMC are met. For one, there is a geographic maldistribution of PCPs, with a higher concentration of providers in well-resourced, metropolitan communities compared to rural areas (Strasser et al., 2022). However, individuals with medical complexity are geographically dispersed, with one study finding similar proportions of CMCs living in rural, urban, and suburban areas (Martin, 2020). The shortage of PCPs in rural areas poses additional challenges for the YAMC given the intensity of the population’s service needs and, in some cases, disabilities that make travel to urban locations difficult. (Li et al., 2022).

There are key training, knowledge, and competency gaps among many PCPs pertaining to care transitions, childhood-onset conditions, and disability accommodations and rights that contribute to provider discomfort in providing care for YAMC and other populations with complex medical needs (Iezzoni et al., 2022; Nehring et al., 2015; White & Cooley, 2018; Zhou et al., 2016). However, clinical training opportunities to prepare PCPs for HCT and to care for the YAMC population are not widely available and have historically been concentrated in Medicine-Pediatrics (Meds-Peds) residency programs (Berens & Peacock, 2015; Nehring et al., 2015). The limited pool of Meds-Peds physicians cannot be relied upon to provide care for the national population of YAMC. Additional training is needed for primary care trainees more broadly – at the undergraduate and graduate levels – as well as for practicing clinicians through continuing medical education. Professional societies and patient organizations have developed competencies and guidance to promote provider training in caring for individuals with disabilities (Alliance for Disability in Health Care Education, 2019), complex care needs (Koppel et al., 2020), childhood-onset medical conditions (Spina Bifida Association, n.d.), and HCT (Got Transition, 2020) that, if adopted more widely, could raise the floor of PCP competencies related to these areas.

Even when adult PCPs are willing to take on YAMC patients, they may be constrained by the structural factors discussed throughout this report, such as the lack of adult complex care interdisciplinary teams, highly fragmented systems of care, insufficient supports and services (e.g., designated staff, time, care coordination and consultation services), and payment systems poorly designed to meet the needs of patients with complex medical needs. Though these constraints present barriers to the delivery of high-quality primary care for YAMC, PCPs continue to be recognized as the linchpin in complex care best practice models (National Governors Association, 2017; Long et al., 2017). In fact, PCPs strive to provide optimal care for complex patients despite the system and local level barriers they encounter. Some, for example, have reported personal sacrifice and putting patients' needs above their own to ensure patients received the care they needed (Loeb et al., 2016). Though noble, this finding is concerning and speaks to the inadequacy of current resources and policies to support PCPs in caring for YAMC and other complex care populations.

**ADVISORY COMMITTEE CONCLUSION:  
Primary Care Workforce for YAMC**

Strengthening the primary care workforce for YAMC requires growing the cadre of PCPs who specialize in working with this population while also enhancing the capacity of all PCPs to have the knowledge to provide a basic level of care for YAMC. The specialized nature of complex care delivery stems largely from the breadth of the care teams and the need for coordination of the medical and community services required. PCPs already possess many of the competencies and skills needed to provide YAMC with high-quality primary care. These competencies and cross-cutting care approaches should be emphasized and augmented with training to prepare PCPs to work on interdisciplinary care teams within the larger health and community systems context. However, PCPs' potential roles in the care of YAMC will not be optimized without needed infrastructure and financing supports. As one Committee member put it, "I can't treat you, because I don't have the resources." Therefore, strategies to strengthen the primary care workforce for this high-need population must be embedded in a broader effort to achieve a health care delivery system committed to the tenets of high-quality primary care, especially care coordination.

## Conclusion

YAMC are an often-overlooked patient population for whom the adult system of health care is not well-prepared to receive. If properly supported, adult PCPs are primed to play an integral role in the care of YAMC and the management of their medical and psychosocial needs. Yet multiple barriers, mostly rooted in health systems infrastructure deficiencies, hinder the primary care workforce from playing a more dominant role in YAMC care delivery. Strengthening the adult primary care workforce to improve care access and delivery for YAMC will necessitate multi-level, cross-sector solutions to address workforce and health care system deficiencies, while leveraging the potential contributions of PCPs. The next section presents a set of recommendations to advance these efforts. Though the recommendations were developed in response to the needs of the YAMC population, the Committee asserts that their adoption would promote high-quality primary care for other medically vulnerable populations, as well.

## RECOMMENDATIONS FOR STRENGTHENING THE ADULT PRIMARY CARE WORKFORCE FOR YOUNG ADULTS WITH MEDICAL COMPLEXITY (YAMC)

### Prepare the Future Health Workforce to Care for YAMC

#### **Goals:**

- To assure that new adult PCPs have a minimum competency related to caring for YAMC transitioning to adult primary care.
- To develop a cadre of adult PCPs with expertise to be leaders in the care of YAMC.

#### **Recommendation 1:**

Require medical, nurse practitioner (NP), and physician assistant (PA) students and residents in family medicine and internal medicine to have a minimum exposure to the needs of complex patients with childhood-onset medical conditions through curriculum and experiential learning opportunities.

- The curriculum at medical schools and in NP and PA programs should include experiential opportunities to learn about children, adolescents, and young adults with complex medical needs. Ideally, experiential opportunities would include direct exposure to these patients during clerkship rotations or other clinical requirements. However, patient simulations, interactive case studies, and role playing with YAMC could also provide students with valuable learning opportunities as part of existing courses and rotations.
- Internal medicine and family medicine residency programs should expose residents to children, adolescents, and young adults with complex medical care needs.
- Medical, NP, and PA education accrediting bodies should incorporate requirements for accreditation that schools/programs provide a minimum exposure to children, adolescents, and young adults with complex medical care needs.
- Health professions education associations should work with patient advocacy groups, academic institutions, and professional associations to develop and disseminate guidelines, model curriculum, and technical assistance to educational institutions and educators for greater exposure in the education process to the needs and clinical recommendations for adolescents and young adults with complex medical needs transitioning into adult care. This curriculum should include:



- Basic understanding of childhood-onset medical conditions with medical complexity and associated disability (e.g., cystic fibrosis, cerebral palsy, spina bifida, sickle cell disease, congenital heart disease),
  - Pediatric-to-adult transitional care,
  - Interprofessional education in team-based care (e.g., patients, families/caregivers, PCPs, specialists, social workers, and navigators) for medically complex patients,
  - Care coordination across health and social sectors,
  - Social determinants of health,
  - Mental/behavioral health needs and developmental needs of YAMC, and
  - Disability rights and decision-making supports.

Comments:

While the number of YAMC patients seen by most PCPs may be limited and many of these young adults will also need care of specialists, the PCP plays a critical role in caring for this high-need population. While each school and residency program have responsibility for preparing their students/residents, organizations like the Association of American Medical Colleges (AAMC), the Physician Assistant Education Association (PAEA), and the American Association of Colleges of Nursing (AACN), can assist and promote increased exposure and curriculum revisions. Further, accrediting bodies can promote by incorporating requirements into the accreditation standards and process.

While curriculums are already crowded, and there are many competing demands for the time of students and residents, a strong case can be made that this preparation is not only essential for care of YAMC, but these skills and competencies will be valuable for caring for all patients with complex needs.

At the graduate training level, the Health Resources and Services Administration’s (HRSA) Bureau of Health Workforce (BHW) should consider making funding available for curriculum and experiential learning opportunities through its Primary Care Training Enhancement grants, which support the training of physicians and PAs. The BHW also funds advanced nursing programs which could also be used to support this training.

**Recommendation 2:**

Establish fellowships for adult PCPs, NPs, and PAs focused on YAMC to build a cadre of leaders in care, research, and policy.

- Academic medical centers should establish fellowship programs to prepare leaders in the care of YAMC, the education of future practitioners, and research to support a coordinated and continuous clinical pathway for adolescents and young adults with complex medical care needs moving from pediatric to adult care. Fellowships would create a pipeline of new clinical experts and researchers, as well as offer expanded training opportunities for current practitioners, thus providing a strategy for leveraging the existing health workforce to strengthen adult primary care for young adults with complex medical needs. The current Transitional Care fellowship program at the University of Rochester Medical Center is one model for such a program.

Comments:

Federal agencies and the philanthropic community have a long track record of offering fellowships to build expertise and develop leaders in an area of need. Support in the form of new funding announcements could come from HRSA’s Maternal and Child Health Bureau (MCHB) and its BHW as well as the National Institutes of Health (NIH), the Agency for Healthcare Research & Quality, and private foundations.

## Support the Current Adult Primary Care Workforce to Care for YAMC

### Goals:

- To provide support to adult primary care practitioners for the care of YAMC.
- To create an infrastructure to provide care for YAMC and support adult PCPs caring for these them.

### **Recommendation 3:**

Build on existing training infrastructure supported by the federal government to train and provide technical assistance to existing and future PCPs related to care for YAMC.

- Federal programs that provide assistance to practitioners and individuals with complex medical needs should expand to provide training and technical assistance to support adult PCPs serving YAMC. Programs include:
  - The interdisciplinary **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** programs, which provide graduate-level interdisciplinary training through 60 programs across the country to improve the care of infants, children, and adolescents with disabilities. These LEND programs could provide short-term training and continuing education opportunities for adult primary care trainees and clinicians on the care of YAMC. The program is administrated by MCHB.
  - The **Developmental-Behavioral Pediatric Training Programs**, which could also provide short-term training and continuing education programs to adult primary care trainees and practitioners who serve adolescents and young adults with developmental and behavioral disabilities. There are 15 programs, which are administrated by MCHB.
  - **National Training and Technical Assistance Partners (NTTAP)** programs, which could support technical assistance to FQHCs on the provision of care to YAMC. The national network of FQHCs provides a significant share of primary care services to high-need and underserved populations in the United States. These programs are operated by HRSA's Bureau of Primary Health Care (BPHC).
  - **University Centers for Excellence in Developmental Disabilities (UCEDD)**, which work with people with disabilities, members of their families, state and local government agencies, and community providers to provide training, technical assistance, services, research, and information sharing, with a focus on building the capacity of communities to care for all of their residents. There are 67 centers, in every state and territory, and they are supported by the US Office of Intellectual and Developmental Disabilities (OIDD), within the Administration on Community Living (ACL).

### **Recommendation 4:**

Create state or regional Centers of Excellence for the care of YAMC to facilitate knowledge sharing among pediatric and adult PCPs and specialists providing care for YAMC.

- Academic health centers should develop state and/or regional Centers of Excellence to provide remote consultations for practitioners, patients, and family members and offer training and technical assistance to FQHCs and other community-based health centers. The centers would:
  - Serve as a resource for community-based PCPs, YAMC, and family members in their state or region,

- Support the expansion of community-based adult PCPs interested in caring for YAMC by providing direct consultation and care coordination services and developing resources and guidance to support them in YAMC care delivery,
- Coordinate closely with pediatric complex care sites,
- Implement pediatric/adult complex care learning communities using established tele-education models, like Project ECHO,
- Facilitate the education of future practitioners in the field by serving as a clinical teaching and learning site, and
- Undertake research.
- Supportive federal and state policies should be adopted to optimize centers' impact:
  - People with disabilities should be legally identified as a Special Medically Underserved Population and the Centers of Excellence that provide their direct services made eligible as a HPSA Other Facility under the authority of the Public Health Service Act. This would make them eligible as practice sites for clinicians under the National Health Service Corps (NHSC) and facilitate provider recruitment. This is consistent with a recommendation of the National Council on Disability (National Council on Disability, 2022).
  - CMS and state Medicaid agencies' policies permitting reimbursement for telehealth services within and across state lines would greatly facilitate access to and regionalization of centers.

Comments:

While the long-term goal is a nationwide network of state centers of excellence, in the shorter term, regional centers should be established. Funding for these centers could come from demonstration funding through combined federal funding from agencies including MCHB, BHW, CMS, and ACL.

### Payment Policy to Support Adult PCPs in Serving YAMC

**Goals:**

- Encourage community-based PCPs to serve YAMC.
- Provide enhanced payment and new financial incentives for adult PCPs caring for YAMC.
  - Reinforce aligned payment recommendations already identified by national expert and consensus bodies and tailor them to the YAMC population (Long et al., 2017; National Academies of Sciences, Engineering, and Medicine, 2021; Humowiecki, 2018).

**Recommendation 5:**

Establish payment arrangements that incentivize and support PCPs in providing care to meet the care delivery needs of YAMC.

- Fee-for-Service (FFS): In line with calls from the national Advisory Committee on Implementing High-Quality Primary Care to increase payment rates by 50% for primary care services (National Academies of Sciences, Engineering, and Medicine, 2021), under FFS arrangements, fees to PCPs should be increased to attract more clinicians into the field and to enable practices to invest in care teams and processes. In addition, payers should recognize CPT codes for services integral to YAMC care delivery, including office and home visits, telehealth, care coordination, care planning, HCT, and specialist consultations (Schmidt et al., 2022).

- **Alternative Payment Models (APMs):** Increase adoption of APMs, which are better aligned with quality of care and offer greater flexibility than FFS models. These models include infrastructure investments, pay-for-performance, per member per month payments, bundled payments, population-based payments, and direct payments to patients. Alternative payment models should consider the infrastructure, services, and care coordination activities that comprise an effective adult medical home or consultation model for YAMC. Using the pediatric medical complexity definition and CCC+ algorithm (described in Section 2 of this report) would aid payers in identifying the target population for development of APMs.
- **Hybrid Payment Models:** Expand the use of hybrid payment models, which combine FFS and capitated payments, to support team-based primary care.
- **Quality Measures:** Encourage the use of financial incentives aligned with quality measures including:
  - **Structural measures:** such as assignment of accountable pediatric and adult PCPs; capacity of adult primary care system and linkages with specialty care, hospital services, and community-based supports; data sharing; use of telehealth; and exchange/reconciliation of current medical information.
  - **Process measures:** such as evidence of collaborative planning between pediatric and adult care with transferring YAMC, informational continuity/communication between pediatric and adult care settings, and receipt of transfer assistance.
  - **Outcome measures** such as patient/family experience, adherence to care, quality of life, changes in symptoms/severity/functional status post-transfer, and primary care/ER/hospital care utilization.

**Recommendation 6:**

Embed care coordination and other infrastructure supports within all payment models for adult PCPs serving YAMC.

- Establish payment arrangements to support care coordination staff for adult primary care practices seeking to care for YAMC.
- Financial incentives are warranted not only for care coordination but also for other infrastructure supports, including accommodations, electronic health record interoperability, 24/7 phone access/consultation, and continued workforce development and quality improvement supports. Payers also need to recognize added non-face-to-face time and work necessary to care for a smaller panel of complex care patients versus a traditional primary care practice.

**Comments:**

These recommendations are rooted in the shared belief that current payment structures, especially FFS, are a major barrier to achieving high-quality primary care and scaling and spreading effective models of care for patients with complex medical needs.

Additional research (See recommendations 8 and 9) is needed to inform the appropriate level of enhancement of payments based on patient population characteristics, anticipated care needs, and scope of enhanced services provided.

**Recommendation 7:**

CMS should use its Innovation (CMMI) Center funding and state Medicaid agencies should use their existing authorities to support payment and delivery models that promote safe, effective, and integrated adult primary care for YAMC.

- Leverage CMS funding to test and evaluate the expansion of payment models that promote comprehensive adult primary care in partnership with pediatric complex care, behavioral health, and specialty care systems, in line with CMS’s stated strategic objective to support care innovations for integrating whole-person care (CMS Innovation Center, 2021).
- Encourage states to create and pilot a transition episode-based payment for accountable pediatric and adult providers to ensure a planned transfer from pediatric care and integration into adult primary care (McManus, 2022).
- Encourage state Medicaid agencies to extend childhood eligibility status to YAMC to age 26 to reduce disruptions in eligibility and benefits.<sup>1</sup>
  - Encourage state Medicaid agencies to expand their targeted case management benefit for youth and young adults with complex care needs to ensure the coordination of transition planning, transfer, and integration into adult care.<sup>2</sup>

## Support for Research to Improve Care of YAMC

### Goal:

- To support a robust research agenda focused on YAMC, including to enhance understanding of the current landscape of complex care and workforce needs.

### **Recommendation 8:**

Increase federal research support to build the evidence base for primary care delivery and related workforce strategies for YAMC, including through the establishment or enhancement of an existing research center.

- The HRSA National Center for Health Workforce Analysis, which currently funds nine Health Workforce Research Centers targeting specific groups of health practitioners, should consider funding a new center focused on the workforce for individuals with medical complexity, including YAMC, or expanding an existing research center to include this workforce. HRSA’s MCHB also supports research programs that could be leveraged to contribute to this effort. Priorities of the research center should be to:
  - Analyze Medicaid and all-payer claims data to better understand the current and projected YAMC patient population, practitioners and their utilization patterns (e.g., patient demographics, diagnoses, services rendered, insurance source, utilization, costs).
  - Conduct statewide assessments of current pediatric and adult complex care supply, distribution, and capacity. This would be a valuable early effort, and findings can inform the data-driven workforce development and investment strategies to address population needs.

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<sup>1</sup> Oregon, through an 1115 waiver authority, extended income eligibility for those ages 19 to 26 with 2 years of continuous eligibility if they have: one or more serious chronic conditions as represented by the Pediatric Medical Complexity Algorithm’s list; a serious emotional disturbance or serious mental health issue; a diagnosed intellectual or development disability through the state’s Office of Developmental Disabilities Services, or an elevated service need or functional limitation as determined by two or more affirmative responses to a screener.

<sup>2</sup> Massachusetts, through its 1115 waiver authority, amended its targeted case management benefit to individuals under 21 who: require ongoing medical management by at least 2 pediatric subspecialists; have a functional impairment or a condition that must be progressive, expected to last a year or longer and be episodically or continuously debilitating or a progressive or metastatic malignancy; and be at high risk for adverse outcomes and require more than 2 continuous hours of skilled nursing to remain safely at home.



- CMMI has identified integrated primary care models as a key learning area and next step for improving care quality and access for Medicare and Medicaid beneficiaries with complex medical needs (Fowler et al., 2022). CMMI should continue to invest in the development and evaluation of innovative models that promote integrated care delivery for patients with complex needs. These investments will aid in identifying evidence-based best practices, which CMS should disseminate broadly to help scale and spread effective models.
- CMMI should provide continued financial and technical support to state Medicaid agencies to implement and scale models of care delivery for YAMC that strengthen the roles of PCPs and are rooted in care coordination and interprofessional collaboration, working with both pediatric and adult care settings. These could include enhanced primary care and consultative/care coordination models.

Comments:

Efforts to ensure an adequate and well-prepared workforce to care for YAMC have been hampered by the lack of data on the current and projected size of this population, their needs, their use of services, and the practitioners who serve them.

**Recommendation 9:**

Establish a Pediatric and Adult Complex Care Research Network to improve continuity of care between pediatric and adult care and to efficiently expand and assess adult primary care capacity to serve the growing population of YAMC.

- Expand Practice-Based Research Networks (PBRNs) to include a PBRN for Pediatric and Adult Complex Care that could help address the definitional and evidence gaps that stymie primary care delivery and access for individuals with complex care needs. PBRNs are groups of PCPs and practices working together to answer community-based health care questions and translate research findings into practice (Agency for Healthcare Quality & Research, 2018). They engage the clinicians on the ground in defining and advancing research agendas to improve primary care for populations including pediatric patients, vulnerable populations, and rural communities. Efforts could include:
  - Comparative-effectiveness research in care delivery, payment reform approaches, care continuity and coordination, clinical decision-making, and organizational systems (based on patient and provider outcomes, costs, etc.), and dissemination of best practices,
  - In concert with Recommendation 8, leading efforts to define the patient population and/or develop patient taxonomies based on clinical presentation or other factors, and
  - Defining relevant outcomes of interest for this high-need population, for which conventional health care quality outcomes are lacking.
- Future MCHB complex care collaboratives should focus on transitional care for YAMC, working in partnership with pediatric and adult complex care and their LEND training programs and state family networks.
- Support health services research and dissemination and implementation interventions to develop the evidence on what models of care work best in diverse communities and what strategies are most effective to implement, scale, and spread them.

The Agency for Healthcare Research and Quality (AHRQ) has supported the PBRNs in the past, while MCHB currently supports a pediatric complex care collaborative and its LEND programs.

## Build a Coalition of Interested Organizations to Support Expanded Adult Primary Capacity for YAMC

### **Goal:**

- Build a coalition to refine recommendations and proposals and advocate for the adult primary care workforce and service delivery system for young adults with complex care needs.

### **Recommendation 10:**

Convene a series of meetings with key stakeholders interested in improving adult primary care services available to YAMC to present findings and recommendations from this report and to build a coalition to support implementation and follow up activities.

- MCHB, with support from the BHW, CMS, and ACL, should convene a group of key stakeholders, including young adults and their families, who are committed to the care of individuals with complex medical needs and are interested in supporting an infrastructure that can help ensure a smooth transition from the pediatric care system to an adult care system responsive to YAMC.
- The stakeholder group should disseminate the findings of this report through webinars and presentations and advocate for the report's recommendations.
- MCHB and private foundations should support the formation of a coalition of advocates for YAMC to further advocate for the report's recommendations and support implementation and follow up activities.

### **Comments:**

Obtaining support and implementing the recommendations in this report will not be easy. It will require a concerted effort by those committed to the care and lives of individuals with complex medical needs. There are many groups and organizations that have an interest in supporting an infrastructure that can help assure a smooth transition from the pediatric care system to an adult care system responsive to YAMC; and, of course, there are thousands of young adults and their families and friends who are deeply aware of the need for a system of care.

A major challenge is bringing these diverse groups together to advocate for the recommendations in this report. A good place to start is the dissemination of this report through webinars and presentations. This could be followed by the formation of a coalition of advocates for YAMC. This requires organization and financial support, which can come from agencies like MCHB that provide enormous support for children as well as from philanthropic support from private foundations committed to strengthening the primary care workforce for this high-need, poorly-supported patient population.

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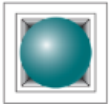
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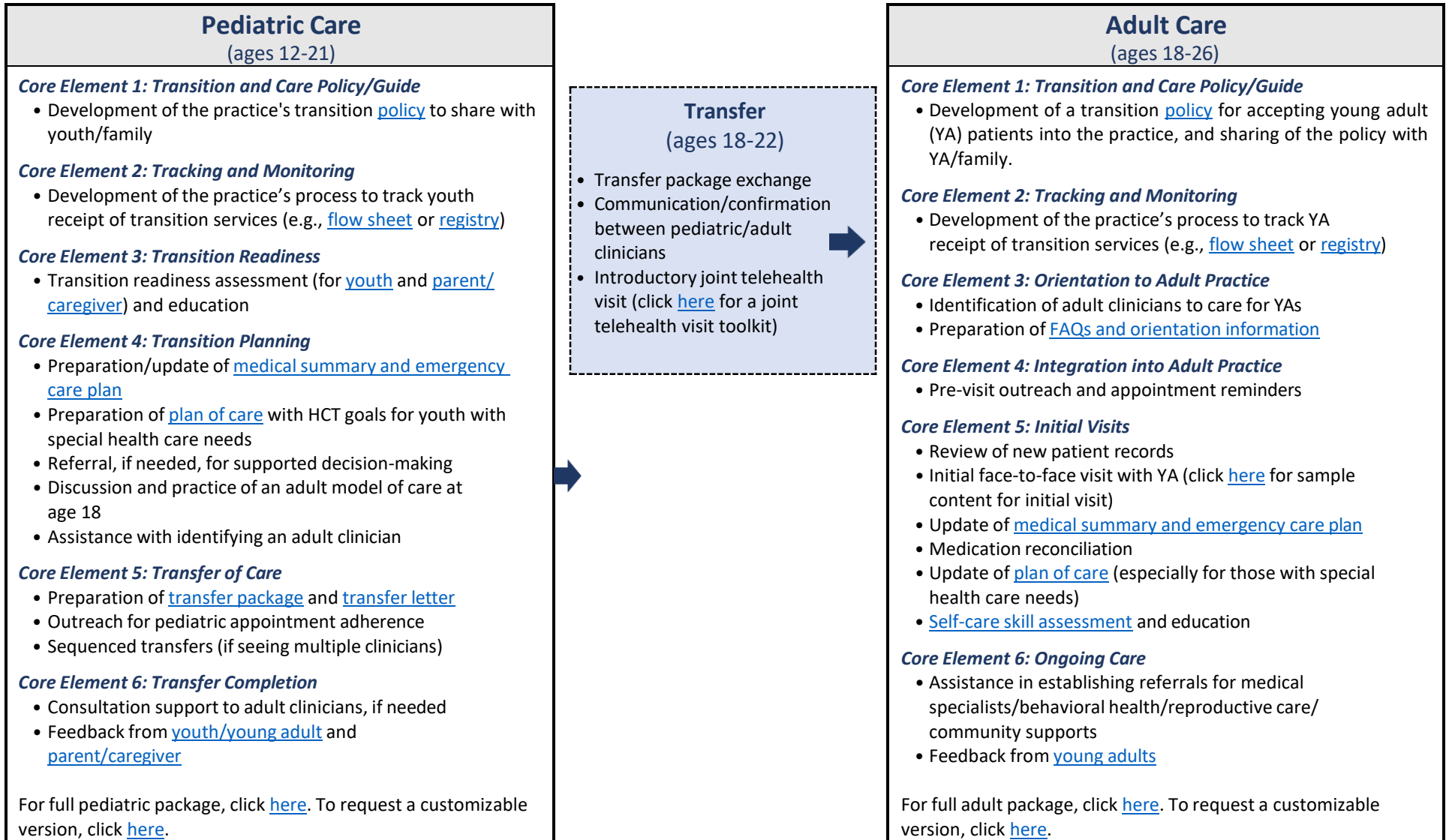
We would like to thank Julie Orban, MPH for her instrumental help with the initial phase of this work.

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## APPENDIX B: DELINEATION OF HEALTH CARE TRANSITION ACTIVITIES AND TOOLS



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