STRATEGIES FOR CHANGING STATE MEDICAID POLICY TO IMPROVE SERVICES TO CHILDREN WITH MEDICAL COMPLEXITY

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Introduction

Children with medical complexity (CMC) are a growing population disproportionately covered by Medicaid for their healthcare needs.[1] It follows that Medicaid policy has a major impact on healthcare access and quality for CMC. As an exceptionally large public program serving more Americans than Medicare, Medicaid also has influence on broader state health policy and can influence the design of state commercial health insurance coverages for CMC. This paper will introduce a number of existing Medicaid policy instruments and then explain how they can be used more effectively for programs and providers dedicated to serving CMC. Because Medicaid programs are so variable across the nation, this paper also will provide a diagnostic approach to understanding each state's Medicaid policy and service delivery system environment. The different environments shape decisions about which Medicaid policy instruments will be most effective in improving services for CMC. Finally, strategies of different scale are offered to demonstrate how policy can be changed in increments from targeted to transformative. The ultimate purpose is to improve the service delivery system for CMC and their families, which can be accomplished in many ways.

A unique and key challenge around CMC is the lack of a universal definition of the population and especially the ability to operationalize a common definition. This could merit its own discussion but for our purposes it is sufficient to point out that the literature cites, often without qualification, CMC prevalence levels ranging from 0.5% to 6%.[2–5] Rather than try to impose a definition, this paper leaves that as a choice for the reader in their particular circumstance.[6] The bottom line is that this process is offered for your purposes in your environment.

Background

Medicaid is a program where federal and state governments share responsibility. The federal government provides a policy framework with a range of flexibilities and states make policy choices within that framework. For example, states range in how narrow or expansive their eligibility and covered services policies are, within allowable federal parameters. A document called the State Plan describes each state's Medicaid policies, service delivery structures, and reimbursement methods, serving as an intergovernmental contract that is dependent on federal approval. This is a living document that changes regularly, primarily through "State Plan Amendments (SPA)". Medicaid legislation also allows for waivers which operate outside of the standard State Plan constraints.[7]

Medicaid and Children and Youth with Special Health Care Needs (CYSHCN) programs are expected to work together for the mutual maximum benefit of the CYSHCN population. Each state has a CYSHCN program federally funded by the Health Rehabilitation Services Administration (HRSA) through the Maternal and Child Health Block Grant under Title V of the Social Security Act. Federal law and regulation intend that programs funded by Title V give policy direction and influence service delivery structures for the affected Medicaid populations.[8] This is especially relevant for state CYSHCN agencies that are tasked with improving service quality and health outcomes for the CYSHCN population, a responsibility that should be negotiated and then defined through a federally required interagency agreement between Medicaid and CYSHCN agencies.

Within this framework, the intensity of need for CMC and their families should merit special emphasis for this key subpopulation within the larger CYSHCN target population. CMC can easily get lost in public health's population health focus, and in Medicaid's concern about the higher costs of the larger population of disabled adults, as well as other cost drivers. That is why it is so important that CYSHCN programs and other key stakeholders (e.g., complex care providers) understand the unique Medicaid policy tools that have the ability to improve services and delivery systems for CMC.

The recently adopted ACE Kids Act[9] highlights the needs of CMC and their families and brings with it potential federal and state support for developing and improving the service delivery systems entrusted with the care of CMC. While Medicaid can seem intimidating and impenetrable by its size and complexity, its mandate calls for a coordinated approach with Title V agencies in developing improved service delivery systems for CMC. This toolkit will endeavor to make Medicaid more understandable and provide a range of strategies that may be useful depending on different state Medicaid program policies and structures.

Policy Tools for Advancing Care for Children with Medical Complexity

States have many policy instruments available to make changes to their Medicaid programs. These tools generally are the product of federal legislation, some longstanding while others are more recent in origin. This section will provide a brief overview of the different tools that are useful for improving services for CMC. These policy instruments will be revisited later when addressing how they can be applied most effectively. It should be kept in mind that each of these policy instruments has a different purpose and, therefore, accomplishes a different objective.

ACE Kids Act[9]

Description: This is new federal legislation to "establish a State Medicaid option to provide coordinated care to children with complex medical conditions through health homes" that was signed into law on April 19, 2019, but not effective until October 1, 2022. The thrust of this legislation is to build a system of care for CMC and establish health homes as the anchor. The legislation brings its own definition of CMC, one that appears to be in the intermediate range of those put forward in the literature. The health homes are defined by substantial requirements for coordination of appropriate services from the full range of appropriate providers, including out-

of-state specialty centers. There is considerable latitude for how the health home might be constituted, from a designated individual provider to a team of health professionals to a health team with locations ranging from the community (including Federally Qualified Health Centers) to more institutional settings (e.g., hospitals). Enhanced payment for health home services is assumed if the state adopts ACE Kids, but there is broad latitude in terms of reimbursement methodology. It includes an increase of 15% to the Medicaid matching rate up to 90% for the first two quarters following adoption as a federal funding incentive.[9] This policy is optional for state Medicaid programs and uses the State Plan Amendment (SPA) process.

Use for CMC Programs: Adoption of the ACE Kids Act by a state is a commitment to building a system of care for CMC. Service delivery systems focused on CMC can/should be part of that system of care and should benefit from the effort to better serve CMC. Since this policy is optional for states, it can serve as a focal point for advocacy to shine a light on the need to better serve CMC and their families.

Family Opportunity Act (FOA)[10]

Description: This federal legislation was adopted as a part of the 2005 Deficit Reduction Act. It provides the opportunity for states to expand Medicaid eligibility to children with a "severe disability", defined as meeting Supplemental Security Income (SSI) criteria. For families with incomes below 300% of the federal poverty level (FPL), they can buy in to Medicaid for their qualifying child regardless of whether the child is covered by commercial health insurance.[10] As with the ACE Kids Act, this expansion is optional for states, and would be enacted by states as a SPA.

Use for CMC Programs: Programs that provide comprehensive services to CMC can benefit from having more of their population enrolled in Medicaid, as enabled by the FOA. This assumes that their Title XIX state agency (i.e., Medicaid agency) appropriately reimburses for intensive care coordination and non-traditional services not typically covered by commercial health insurance.

1915 Home- and Community-based Service Waivers[11]

There are a host of 1915 waivers and authorities, each designated with its own extension (e.g., "1915(b)"). Most states have adopted some combination of these, most of which waive freedom of choice of providers or provide enhanced home and community-based services (HCBS) for high-need individuals. Collectively these 1915 waivers and authorities offer a dizzying array of options. They are usually modest in numbers and impact but any one of them can be a lifesaver to a specific group of children and their families.

The 1915 waivers and authorities most applicable to CMC are those that provide for expanded long term supports and services, which more typically include disabled and older adults, but can cover high-need children. Children are often singled out as a specific target population in a separate waiver. These waivers have a number of forms including (c), (i), (j), and (k).

A brief description of each is outlined in Table 1.

Table 1. Description of 1915 Waivers and Other Authorities

Waiver/authority	Description & uses	Requirements & specifications
1915(c)	Have been in place for the longest time, are the most common, and require that covered individuals meet standards for an institutional level of care (e.g., hospital or nursing home). The need for institutional care enables the state to disregard parent income and resources in granting financial eligibility and enables the coverage of home and community services that exceed those routinely covered under the state plan.	These waivers must be budget neutral, can be targeted to a very limited subpopulation, and typically have an enrollment cap.
1915(i) authority	Provides long term supports and services beyond those in the state plan for beneficiaries who meet a functional standard that justifies special supports.	This provision differs from (c) waivers in that it allows states to establish a functional standard below the level of institutional care, and does not require budget neutrality, but does prohibit enrollment caps (which can give states budget angst). This authority is activated by a SPA.
1915(j) and (k) authorities	From the Affordable Care Act, these authorities empower individuals and families to assert more control over the application of resources and choice of individual caregivers.	Both require that individuals meet the institutional level of care standard and that other normal Medicaid principles are followed, including availability on a statewide basis and no enrollment cap.
1915(b) waivers	Focus is on freedom of choice. This provides state Medicaid agencies with the ability to impose restrictions of the providers that a beneficiary can access. A common example is limiting beneficiaries to one contractor that provides non-emergency transportation services. This can be used for a specialty MCO or contractor that provides a special type of service for CMC and	The state Medicaid agency is required to demonstrate that a sufficient number of qualified individual providers are available so that access to quality services is assured.

	limits enrolled children to that MCO or contractor.	

It is noteworthy that the expansion of HCBS has recently been at the forefront of congressional discussions. The COVID-19 pandemic has made it clear that persons institutionalized are at greater risk for a range of poor outcomes, and that care at home or in the community is often a preferred option with better outcomes. Since Medicaid policy currently makes HCBS programs largely optional for states, with waiting lists being more the norm than exception, mandating this coverage has been proposed in the form of the HCBS Access Act (HAA). It was introduced about a year ago and is expected to be revisited in this congressional session.

This potential change makes a broader point that Medicaid policy is dynamic and that any static presentation of information (like this paper) can be outdated on specific points relatively quickly. To the extent that policy changes improve the "system", so be it.

The Tax Equity and Responsibility Act (TEFRA) SPA[12,13]

Description: This also is known as the "Katie Beckett" option, the name of the child who inspired this policy after living in the hospital until age 3. Her parents' income disqualified her from Medicaid coverage in the home and the parents' private insurance did not cover home care. TEFRA allows states to disregard parental income for children who meet SSI medical disability criteria and qualify for an institutional level of care according to the functional eligibility criteria set by the state. This is as an optional State Plan group and serves as an alternative to the 1915(c) approach.

Use for CMC Programs: TEFRA is specifically responsive to CMC and their families. This is limited to only those CMC meeting an institutional level of care. The key benefit is the ability to qualify children for Medicaid by disregarding parent income. Benefits are those provided through the state plan.

Federal Regulation 431.615(c)(2)[14]

Description: This federal authority requires that Medicaid State Plans provide for arrangements with Title V grantees, including CYSHCN agencies, in which the Medicaid agency will utilize the grantee to furnish or arrange services that are included in the State Plan. The authority for this approach would be a SPA.

Use for CMC Programs: This can empower the CYSHCN agency to develop and/or authorize a service delivery system to which CMC enrolled in Medicaid would be directed for their health services. This could include designating (or certifying) only certain providers as appropriate for certain CMC as defined under this arrangement. Pediatric complex care clinics that are critical to serving CMC in many states could be one type of designated Title V provider. This could target enhanced Medicaid coverage and payment to only those providers designated by Title V as best equipped to serve the defined CMC population.

Targeted Case Management[2,15,16]

Description: Targeted case management is case management provided only to specific classes of individuals, or to individuals who reside in specified areas of the State (or both).

Use for CMC Programs: CMC can be a designated population for this purpose. The federal regulations do provide for freedom of choice of providers and also limit case management to a single provider at any point in time. However, there are provisions for requiring that targeted case management providers have experience and skills to appropriately serve the designated population making it possible to limit this to CMC specialized settings.

Section 2703 of the Affordable Care Act State Plan Amendment[17]

Description: Health Homes are an optional Medicaid State Plan benefit established by Section 2703 of the Affordable Care Act (ACA). These so-called 2703 programs were created to promote coordination of care for individuals with or at risk of multiple chronic conditions. Designated health home providers integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the "whole person". States that elect this option receive a 90 percent enhanced Federal Medicaid Assistance Percentage (FMAP) for eight quarters for all six health home services including care coordination. Subsequently, the service can be sustained as a regular State Plan benefit at the state's standard services match rate.

Use for CMC Programs: While states cannot target this benefit by age, there is the ability to designate a specific type of provider as the service delivery system and that carries with it the population that is served by that system. Therefore, states could target pediatric complex care programs for CMC as the specific health home provider group. This option also can be targeted by geographic area.

1115 Waiver[18]

Description: These are waivers that essentially throw out the federal Medicaid rulebook. The only limiting criteria are that they cannot change the federal matching rate and that the Secretary (of the federal Department of Health and Human Services) agrees that it promotes the objectives of the Medicaid program. Typically, these must be budget neutral over the waiver time period. Beyond these constraints, almost anything goes if the federal Centers for Medicare & Medicaid Services (CMS) supports the idea as a worthy innovation. CMS will be unreceptive if the design innovations can be accommodated through a SPA or more targeted type of waiver, such as one in the 1915 series. Other challenges include that they require considerable work and the process is protracted. Convincing state government to invest the time and effort and gaining federal support is a high bar.

Use for CMC Programs: The obvious benefit is that 1115 waivers provide a vehicle for the most creative thinking that colors outside the lines of traditional Medicaid. One example that will be discussed below is to develop a program for CMC using a definition that is inclusive of SSI functional criteria and CMC medical criteria, the latter based on the ACE Kids definition or one of your own making. This addresses the fact that there are inconsistent population definitions in two significant pieces of federal legislation.

Early, Periodic Screening, Diagnostic and Treatment or EPSDT

Description: This very broad principle in Medicaid law and regulation provides, among other requirements, for the coverage of any medically necessary treatment services for children, regardless of whether they are covered under the Medicaid State Plan (for each state). At a minimum, this includes all "optional services" specified in the Medicaid statute. However, it can extend to "any other medical care, and any other type of remedial care recognized under state law, specified by the Secretary [of HHS]".[19]

Use for CMC Programs: A key is the definition of "medical necessity" and as noted by the Medicaid and CHIP Payment and Access Commission (MACPAC), "(F)federal law does not define medical necessity and definitions adopted by states vary."[20] There are instances where these principles have been successfully applied to expand covered services like those provided by pediatric complex care clinics.

Internal Assessment – What Does Your Project Need to Sustain its Intervention?

The most direct immediate need for many service innovations is how to financially sustain the intervention beyond the end of demonstration grants or other start-up funding. Finding a revenue stream that supports a sound financial structure into the future is a challenge.

While this document will explore a range of strategies that can be used to enhance Medicaid revenues, the logical beginning point is to gain a concrete understanding of the resources needed to support the service intervention, often a pediatric complex care team, designed to better serve CMC. Even what appear to be fairly straightforward models can turn out to be more complicated when there is scrutiny of the complementary efforts that are required of other actors in the system. For example, where a nurse coordinator or professional support team in a complex care clinic is the primary investment of grant funds in the intervention, there are many other providers, such as community pediatricians, that invest additional complementary effort, and therefore costs, in the care process. It is important to gain a full understanding of the collective additional effort, and their associated costs, required for the intervention to be successful and sustainable over time.

Below are a series of questions/steps offered as a guide to reach that understanding.

1) Who are the providers of intervention services and therefore incurring costs, both internal to the organization spearheading the intervention and those external but participating in some way?

2) How many of these providers are incurring sufficiently substantial costs to require additional reimbursement for their continued participation in the service system? This can apply to other departments in larger organizations like hospitals (e.g., different therapists who may participate in ways beyond just providing direct billable services) or those in the community such as primary care physicians or social/community service providers.

3) What is the time and cost of the various providers/positions of the intervention, particularly that are devoted to care coordination and other support activities that may not

be reimbursable, or for which reimbursement is inadequate for the intensity required for CMC?

Quantifying this can be challenging. While an individual position might be fully committed to the intervention, and therefore their compensation is the simple quantification of their cost, other staff and external providers are likely to be committing only a portion of their time. That partial effort needs to be measured and converted into a cost.

It may be useful to reference work published in Pediatrics 2019;143; DOI: 10.1542/peds.2017-3562 originally published online December 24, 2018; **Estimated Nonreimbursed Costs for Care Coordination for Children with Medical Complexity**, Sarah D. Ronis, Richard Grossberg, Rabon Allen, Andrew Hertz and Lawrence C. Kleinman.[21] They did an incredibly detailed study of the non-reimbursed care coordination time of professional staff in a pediatric complex care clinic. This is likely beyond the ambition or necessity for most CMC focused programs or services, but it does provide an excellent methodological frame of reference.

4) The cost equation includes whether to consider only direct costs or if there is a need to add indirect costs. All institutions have offices that perform internal support functions (like human resources or finance) that typically allocate their costs to revenue-generating units like clinics. A fully loaded cost calculation would typically incorporate these costs but there could be different approaches in different settings.

5) While determining the aggregate costs, and therefore the commensurate needed revenues, is a major step, almost all payers reimburse on a patient-specific basis. This will require that costs be converted into charges for intervention services, whether discrete for a fee-for-service environment or some form of APM such as bundled payments or capitation.

6) Finally, there needs to be an assessment of the payer mix to determine the financial impact Medicaid can make individually. If a bundled or capitated payment methodology is desirable (usually for hefty organizations like health systems or ACOs), the necessity of having external providers reimbursed by the central organization must be determined.

A big first step is to get Medicaid to provide adequate reimbursement to cover the costs of the enrolled children, so you need to know your ask. The steps laid out in this section hopefully are adequate to achieve that result. While Medicaid will cover a significant portion of the CMC patient population, we recognize that does leave those with other health insurance and the uninsured as potentially unreimbursed costs. Taking the Medicaid model to the largest commercial health insurers is a future step that is beyond the scope of this paper.

Needs Assessment - State Environmental Scan

States vary greatly in terms of their current service environment for CMC. While Medicaid is the focus, each state has broader healthcare policy and system factors that should be considered. Understanding each state's unique Medicaid program and healthcare environment is critical to

crafting a state specific strategy to improve and expand the service delivery system targeting CMC.

Core environmental factors include:

1) Eligibility: Who qualifies for Medicaid?
2) Benefits: What services are covered?
3) Service Delivery Structures: What service delivery structures are controlling?
4) Reimbursement: How much is paid?
5) General Context: What is the state's health policy environment?

Eligibility

Health insurance coverage levels for CMC are important for both the population and the providers who serve them. The higher the percentage of those covered by health insurance, the better the financial environment for families and providers. Medicaid is uniquely important because of its special role for vulnerable populations like CMC and the innovative policy options at its disposal. Medicaid becomes advantageous both as a primary and secondary source of coverage because it may cover and reimburse for services beyond those of commercial health insurance. So, the higher the percentage of CMC covered by Medicaid, the better the financial potential for the CMC providers of intensive care coordination and other non-traditional services. (This assumes that a state's Medicaid reimbursement rates are at reasonable levels which is not always the case.)

Health insurance coverage levels are generally very high for children, 93.4% according to recent data.[1] This is largely due to Medicaid and CHIP financial eligibility criteria for children that are more generous than for adults. The Affordable Care Act also has made a positive contribution by making commercial family health insurance coverage more affordable for those <400% of the federal poverty level (FPL).[22]

Despite this overall positive health coverage environment for children, CMC have needs that uniquely create financial stress for their families even with some form of health insurance coverage.[23] This is why federal health policy provides special opportunities to expand eligibility and coverage for CMC through a number of different options. Most states have taken advantage of these special Medicaid options through waivers that expand both financial eligibility and service coverages for CMC as a specific population. A cautionary note is that these waivers for CMC are usually very narrowly defined with institutional care needs as the criteria for qualification. This results in special waiver coverage of a very small number of children who are a fraction of the CMC population as a whole.

Given that the federal government provides many options for states in their service coverage for CMC, it is important to understand what states have chosen to have in place for CMC in order to identify gaps and needs. This enables a strategic analysis of what tools might be most useful in

filling those gaps. What follows is a brief descriptive overview of the key public programs and their eligibility parameters.

Medicaid[18]

Prior to passage of the Affordable Care Act (ACA), states were required under federal law to cover children up to 133% FPL. However, there was little uniformity since many states adopted more liberal financial standards than were required, often using certain income disregards (effectively reducing income) and varying qualifying income levels by age group (<1. 1-5, etc.). Conversion to the ACA required methodology of Modified Adjusted Gross Income (MAGI) greatly simplified the eligibility process by using IRS definitions of income and converting each state's prior qualifying income levels to a fixed percentage of Federal Poverty by age group for each state. Each state's current MAGI-based financial eligibility levels are available on the CMS website "Medicaid.gov".

Children's Health Insurance Program (CHIP)[18]

This state/federal program provides for higher financial eligibility standards for children. It essentially adds another higher income group of children for publicly funded health coverage in a state. The gap between Medicaid and CHIP can vary considerably between states. For example, Minnesota has a gap between 275% FPL and 288% FPL, dramatically smaller than Alabama's range of 141% FPL to 312% FPL. CHIP excludes children with access to health insurance offered by employers (with certain minimum standards related to employer subsidies and coverage) without regard to family income. In some states, the CHIP program uses Medicaid coverage and reimbursement policies, while in others, it is a standalone program with different coverage (often more limited benefits) and reimbursement policies.

Medicaid Waivers and Special State Plan Options

Most waivers and SPAs that expand financial eligibility standards specifically for CMC are in the form of providing home and community-based services as an alternative to institutional care. As such, they typically evaluate only the child's income. This is observable from the large number of 1915(c) waivers that have these characteristics.

Children and Youth with Special Health Care Needs (CYSHCN) Programs (Title V)

These programs vary greatly by state with some paying for direct health services while others focus on care coordination. Some may be more oriented to monitoring and evaluation, understanding unmet needs and then advocating and organizing service delivery responses. It is important to understand the nature of the program in your state and the range of family income that enables coverage, if there is payment for services. Finally, the CYSHCN program relationship with Medicaid and especially the degree of connection and influence is vital in developing effective strategy and advocacy.

Diagnostic Overview

The table below attempts to identify the key attributes of the major public programs and their components that provide health coverage for CMC. This is somewhat oversimplified and will be highly variable by state. It provides a very brief description to give a sense of the range of options available to states. All states have Medicaid and CHIP programs and some combination

of waiver and TEFRA options. Only a few states have adopted the Family Opportunity Act (described earlier under Tools).[24] CYSHCN programs are highly variable with some offering substantial health coverages while others focus more on coordinating care.

Table 2. Key Eligibility Attributes of Programs Providing Health Coverage for CMC

	Medicaid	CHIP	Waiver	TEFRA	FOA	CYSHCN
Income - FPL	≥133%	≤400%	None	None	≤300%	Varies by state
Level of Care	None	None	Institution	Institution	SSI	Varies by state
Benefits	Medicaid	Medicaid or more limited	Medicaid + CM + in-home services	Medicaid	Medicaid	Varies by state
Private Insurance	Allows	Excludes	Allows	Allows	Allows	Varies by state
Premiums	No	Yes	Optional/No	No	Yes	No
Authority	Medicaid State Plan	CHIP State Plan	Medicaid Waiver	Medicaid State Plan	Medicaid State Plan	MCH Block Grant & State Legislation

Hopefully this table is useful in diagnosing the breadth of health coverage for CMC in your state. This is not a short or easy process so please take that into account.

Benefits

Understanding Medicaid coverage of critical services for CMC is an important starting point. Two extremely helpful fact sheets from the AAP and Got Transition provide detailed information on the potential range of codes that describe some of the more critical services.[25,26] The simple questions are "what services are covered by Medicaid?" and "which are important for CMC?". A basic level of information should be attainable from existing Medicaid fee-for-service policies. For instance, care coordination services have a range of CPT procedure codes which should have a covered/non-covered indicator by Medicaid. Similarly, there are procedure codes and modifiers for other vital "non-traditional" (sometimes labeled "non-direct") services such as care plan development, transition services (from pediatric to adult care) and telehealth.

The fact that CMC require very intensive care coordination services beyond those needed by other populations is a critical issue in terms of service definition and payment amounts. Care coordination raises a number of issues that also pertain to some of the other non-traditional services. Care coordination consists of a number of discrete activities described by a range of CPT codes. If covered as a general proposition through state Medicaid policy, these services will be open to all providers for all beneficiaries. Because of this, even state Medicaid agencies that cover care coordination are likely to restrict the range of reimbursable codes as well as the

amounts paid. It is important to examine these coverages and payment amounts carefully to estimate the funding generated for the care coordination services needed by most CMC.

Beyond the basic covered/non-covered question, Medicaid agencies have latitude to limit payment of these services even when covered. These include: under what conditions; to what providers; and the payment amount which could vary based on a range of factors including geographic location, institutional connection, etc.

There also can be variation based on what program within Medicaid controls the service delivery structure. Targeted case management (TCM) is a Medicaid coverage option that limits case management (or care coordination) to a specific population. Waiver programs that include CMC are likely to be different in the coverage, providers, and payment policies from the mainstream state Medicaid service delivery systems. Finally, even the fee-for-service and managed care systems can have considerable differences (See the Service Delivery Structures section below).

Service Delivery Structures and Reimbursement

These two components are hopelessly entangled so this section will combine them and address both.

Sorting this out is critical to knowing the sources of influence and where to focus efforts in seeking funding for the innovative interventions and for other more expansive services that improve outcomes for CMC and their families. The core issues here are the structure that controls payment, the nature of the payment arrangement (reimbursement methodology), and the amount. The structure could be the Medicaid agency itself or managed care organizations (MCOs), accountable care organizations (ACOs), and other entities to which provider paneling, coverage and payment authority has been contractually delegated. The reimbursement methodology also plays a role because more advanced Alternative Payment Methods can move control of funding downstream to provider organizations more directly involved in care (e.g., through bundled or capitated payments to hospitals or physician groups for certain populations).

For this section, a series of questions are presented to work through the many organizational and reimbursement variations.

1) What are your state's Medicaid Service Delivery Structures?

The major structures are state agency direct control through fee-for-service (FFS) with primary care case management (PCCM) as a lightly managed FFS alternative, managed care organizations (MCOs) and accountable care organizations (ACOs) (the latter two generally private), publicly created care management (CM) structures like Regional Accountable Entities (RAEs) in Colorado, and waivers in various forms(here we are classifying the TEFRA state plan option as a waiver because it functions more like a waiver.

The chart below attempts to fill in this information for ten states that developed service innovations to improve quality of care and outcomes for CMC under a HRSA grant.[27] Waiver programs are excluded in Table 3 because those specifically serving CMC are never considered a mainstream delivery system. Given the complexities of every Medicaid program, this by

necessity is an oversimplified rendering. Readers from other states can research their state's Medicaid service delivery system to make a similar determination.

Table 3. State Structure for Medicaid Service Delivery

				Structure		
	Fee-For-				**Public Risk**	**Public CM**
State	**Service**	**PCCM**	**MCO**	**ACO**	**System**	**System**
Alabama		Dominant				ACHN
Colorado		Dominant				RAE
Indiana	Residual		Dominant			
Kentucky	Residual		Dominant			
Massachusetts	Residual			Dominant		
Minnesota	Residual		Dominant			
Oregon					CCO	
Texas	Residual		Dominant			
Washington	Residual		Dominant			
Wisconsin	Residual		Dominant			

2) What service delivery structures do CMC fall under in your state?

Because it is a special population, some states have developed service delivery structures designed for CMC. Below, Table 4 is a modification of Table 3, adjusted to be specific to CMC. In many states, the system will be the same for the broad population of children and for CMC. But for others, there may be an MCO opt-out for CMC with some having special waivers to better serve some of this population. There also can be special MCOs/MCO systems dedicated to a part of the CMC population. Examples are Star Kids in Texas and the Health Services for Children with Special Needs, Inc. (HSCSN) Health Plan in Washington D.C. Note that most waivers typically cover enhanced non-traditional services while the residual mainstream medical services usually are delivered through the fee-for-service system. For this reason, FFS is labeled below as a full partner to states' waiver programs (i.e., both waiver and FFS labeled "Dominant"). This chart could vary for the broader population of CYSHCN. The reader can adjust it to their purposes.

Table 4. State Medicaid Service Delivery Structures Targeted for CMC

	Fee-For-				**Public Risk**	**Public CM**	
State	**Service**	**PCCM**	**MCO**	**ACO**	**System**	**System**	**Waiver**
Alabama		Dominant				ACHN	
Colorado		Dominant				RAE	
Indiana	Half w waiver		Half				Half
Kentucky	Residual		Dominant				

Massachusetts	Residual			Dominant			
Minnesota	Dominant		Residual				Many - Dom
Oregon					CCO		
Texas			Star Kids				
Washington	Residual		Dominant				
Wisconsin	Dominant		Residual				CLTS - Dom

3) For the dominant Medicaid service delivery system for CMC in your state, do they cover the special intervention services and other vital services (such as those specified for health homes in the ACE Kids Act) needed for CMC. And, if so, how?

The services that form each state or regional special service strategy for CMC are likely to be different. In turn, there may be different views on what services are vital for CMC more generally, beyond the basic medical services that should be common to all Medicaid programs. Further, for MCO-type and other forms of delegated care management, there is the question of whether coverage of intervention and/or vital services is uniform or variable across the delegated organizations (e.g., variability across MCOs).

While these variations can make this question challenging, there are a small number of non-traditional services of common interest as a starting point. A core set of non-traditional services are:[26]

(a) care plan development;

(b) care coordination;

(c) telehealth;

(d) transition.

For each of these, try to determine if they are covered by the service delivery system most common to CMC. Then, find out how they are covered and if the healthcare provider entity directly serving CMC is authorized to deliver them. For care coordination, some service delivery systems provide the services themselves (e.g., MCOs, including public, may hire staff to do telephonic or even direct care coordination rather than pay the direct providers of service).

The key for clinics and other providers of direct services is whether the system will cover and make payment for these non-traditional services to them such that all services can be planned and coordinated by the healthcare team. This is a key distinction for care planning and coordination, whether it is covered when embedded within the direct service team, rather than being operated from an external vantage point.

This analytic framework can be adapted for a broader or different patient population such as CYSHCN, a more extensive group of services, and/or a different type of provider organization.

4) How much and how flexible is Medicaid reimbursement? Is it sufficient?

The ultimate question here is whether the amount of reimbursement and/or flexibility of reimbursement can support the ongoing costs of the system effectively serving CMC, often through innovation. It is likely that most providers will need to consider this question in the context of the adequacy of the Medicaid or delegated organization's fee schedule. FFS is still the most common form of reimbursement for providers of direct services whether from the Medicaid agency itself or through MCOs and other delegated organizations. And it is notable that MCO rates are generally built on the base Medicaid agency FFS rates, making it unlikely that the downstream payments from MCOs to their providers will vary substantially in aggregate from that norm.[28]

The question boils down to whether the reimbursement methods and amounts are adequate to financially support the costs of delivering these services at the levels required to be effective for CMC. Underlying this question is whether the fee schedule of the payer recognizes the differential intensity of services being provided for CMC. An assumption that care coordination is equivalent across populations is problematic for CMC providers since more resources are required for this more complex population. The end game is to compare the estimate of revenues generated from the FFS payment to the financial requirements to deliver the service, as determined by the Internal Assessment above.

Alternative Payment Models (APMs) offers reimbursement flexibility but their range confers considerable variance in the delegation of control and risk. The Health Care Payment Learning & Action Network (HCPLAN or LAN) has produced the most widely used APM framework which shows the breadth of models.[29] While there are potential advantages through some form of APM, there are a number of important diagnostic questions:

a) Does the APM actually give control of resource allocation through capitated or bundled payments to the provider organization, or is it more of an add-on payment for meeting quality or other designated metrics?
b) How much control or influence does the CMC dedicated provider(s) have over the distribution of these payments when external providers are involved?
c)If involving risk, how able and prepared is the downstream organization?
d) How substantial is the total APM payment amount and will it support provider costs?

These questions should provide a basis for deciding the potential value to CMC activities and whether an APM arrangement is worthwhile.

General Health Policy Context

Knowledge of the overall state health policy environment is crucial because it sets the stage for any health policy initiative. It is hard to be formulaic here. The core issue is identifying the characteristics of state health policy that are favorable for improving services to CMC. Broader issues provide context such as whether your state adopted the ACA's Medicaid expansion or what level of family income qualifies a child for the Medicaid and CHIP programs.

Beyond the big picture, there are questions that should be helpful with diagnosis relating more directly to the healthcare environment as it pertains to CMC. These are by no means exhaustive but should get you started.

a) Has the state health policy environment generally been affirmative in funding the needs of CMC and their families?
b) Is there indication that the ACE Kids Act will be adopted at the state level?
c) Is the state health policy environment leaning into care coordination and addressing social determinants of health?
d) How influential is the Title V CYSHCN agency in pushing state health policy toward addressing the needs of CMC and their families?
e) Is there a Children's Cabinet or highly placed advisory body that would be accessible for CMC concerns?
f) In general, where are the levers of policy-making authority and how can they be influenced to achieve CMC objectives?

Possible Approaches for Expanded Eligibility, Services or Reimbursement from Medicaid

This section will examine Medicaid policy tools by major program area (i.e., eligibility, services/delivery system related/reimbursement) and also look at funding enhancement strategies. The different tools were introduced and briefly described in the first section. Here, they will be given more comprehensive treatment to show their potential to positively impact CMC and their families. It is important to note that the different policy instruments cited can impact multiple program areas since many have broad objectives.

Approaches to Expanded Eligibility

A relatively small percentage of CMC are uninsured, but many are underinsured. The following Medicaid policy tools fill gaps in different ways and with variable impact depending on current state Medicaid and CHIP eligibility policies.

The Family Opportunity Act[10] *(FOA)*

The FOA provides the broadest and most clearly defined method for expanding eligibility to CMC. Although enacted into law in 2005, only five states have taken advantage of it (CO, IA, LA, ND, and TX). It provides eligibility for children meeting SSI disability criteria with family incomes up to 300% of FPL. This financial eligibility maximum is higher than the limit used for children by most state Medicaid programs although state standards vary from ≤133% FPL to ≤319% FPL for children > age 1. While CHIP programs have higher financial eligibility maximums starting at 200% FPL, they prohibit any child with private health insurance or access to affordable employer subsidized health insurance from enrolling. FOA brings the advantage of allowing Medicaid to serve as secondary coverage, complementing private insurance coverage whether employer sponsored, through the ACA exchanges, or otherwise privately financed. Given that private coverage often has substantial deductibles and copays/coinsurance and is less likely to reimburse for non-traditional services, secondary Medicaid coverage can be a lifesaver for many CMC and their families. The FOA was conceived as a buy-in program allowing states to set premium rates, with ceilings of 5% of a family's adjusted gross income under 200% of the

FPL, and 7.5% between 200-300%. States can set modest premiums and the Act also allows for states to provide premium assistance for commercial insurance coverage. As with the ACE Kids Act, this expansion is an option as a SPA for states. Obviously, FOA adoption will have a very different impact in states depending on Medicaid eligibility thresholds and the buy-in premiums amounts. States are permitted to waive premiums if they so choose.

1115 Waivers[18]

1115 waivers have almost no restrictions so this is where maximum creativity can be applied. It is important to consider what can be accomplished through state plan and more structured waiver options since the federal government will reject 1115 proposals that have not exhausted more routine methods. There is evidence where 1115s expanding eligibility have been approved, and that can serve as a guide here. One in Michigan expanded financial eligibility parameters up to 400% FPL for children in Flint in response to the water crisis.[30] Another expanded the postpartum eligibility time period for women.[18] A CMC-type equivalent might be to extend Medicaid enrollment for NICU graduates up to age 2 or 3 and combine it with more intensive care coordination and increased coverage of community services that address social determinants. A more transformative concept is to extend Medicaid eligibility to CMC meeting either the SSI functional criteria or the ACE Kids Act criteria (which are more medically oriented). That would cover a more expansive range of CMC and reconcile these two different federal definitions.

1915(c), (i), (k), and (j) Waivers[11] ***and TEFRA SPA***[12,13]

Most states have some combination of these waivers and SPAs which are designed to provide home-based, long term supports and services to individuals, including high-need children, in need of institutional level of care (or in the case of (i), a state defined functional level of care). The key is to evaluate what is in place in your state and if there is benefit from a new waiver or TEFRA SPA. Most of the details of these waivers have been covered above when initially described. However, it is worth repeating that these waivers typically have an enrollment cap and waiting lists.

Approaches for Service Delivery System/Reimbursement Innovation

ACE Kids Act

The ACE Kids Act[9] is the best Medicaid policy option for building a system of care for CMC. It calls for effective coordination among and between providers and lays out some fairly specific communication linkages that should be employed. While this strategy can vary in scope, the focus on "system" suggests a broader effort that addresses the many CMC subpopulations rather than one that is narrow. There also are significant quality, monitoring, and reporting requirements that should push each state's evolving system of care for CMC toward continuous improvement. The ACE Kids Act sets the expectation that states will develop specific reimbursement methods and amounts for health home services to CMC that are "consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers" to provide access to care and services comparable to those generally available.[31]

Historically, Title V CYSHCN programs have developed or even operated multi-disciplinary service delivery models for CMC with clear diagnoses that have established evidence-based systems in place. Typically, these models are targeted to children with cystic fibrosis, spina bifida, cleft palate, and other diagnoses that have benefitted from CYSHCN program "endorsement or certification". Since these are diagnostic groups generally defined as meeting CMC criteria and these multi-disciplinary service models have Title V official recognition, they can serve as a foundation for an ACE Kids comprehensive system of care or at least be a complement to or folded into a systems building ACE Kids initiative. These established service models are included here under the ACE Kids Act because they fit a system of care approach, albeit perhaps dated and loosely coordinated. They also can be appropriately addressed by the other Medicaid authorities that follow. Using any of these policies, where they are not already recognized and have their services covered by Medicaid, this is great timing for these service delivery models to gain Medicaid coverage and an appropriate level of reimbursement.

Section 2703 SPA[17]

While not specifically targeted for CMC as is the ACE Kids Act, 2703 SPAs are similar in that they provide enhanced federal match for health home services but for 8 quarters at 90%. This compares favorably to 2 quarters at +15% for ACE Kids. The 2703 SPA option requires that the subpopulation and providers be clearly defined. States are able to create multiple 2703 SPAs for different subpopulations and their health home providers. While 2703 SPAs cannot specify an age group, the state may designate a health home provider system (e.g., a system of pediatric complex care clinics) that has the same effect. Given that neither SPAs to implement the ACE Kids Act, nor the planning grants to get input and prepare, are authorized until October 1, 2022, states might consider using a 2703 SPA(s) as a bridge to or in some combination with ACE Kids. This can activate some of the health homes that will be part of the ACE Kids health home system. Planning grants for 2703 SPAs qualify for the federal services match rate rather than administrative, the same as ACE Kids, so there is no financial advantage in waiting for the ACE Kids Act planning grants.

1115 Waivers[18]

We mention this option again because these waivers give ultimate flexibility so, if no other SPA or waiver option can be identified, an 1115 is always an option. While these waivers can have an unlimited impact, they are varied in scope and include some that are targeted to address specific service delivery issues.

Federal Regulation 431.615(c)(2)[14]

Relying on this regulation, the State Plan can be expanded to cover services provided by pediatric complex care clinics, pediatric health homes, or other systems of healthcare developed specifically for CMC. This would include a Title V certification process that gives these clinics/providers special status for the purposes of the SPA. This can be accompanied by increased reimbursement either through increased fee schedules or the adoption of APMs that fully support the financial requirements of the service system. As a reminder, this federal regulation requires Medicaid to fully support the costs of the designated providers in the service delivery system developed under the auspices of Title V.

Targeted case management[2,15,16]
To repeat the general principle, TCM is case management services provided only to specific classes of individuals, or to individuals who reside in specified areas of the State (or both). CMC, or a subset by diagnosis, functional status, or geographic area, could be designated as that class. This is the mechanism used by the Wisconsin Medicaid agency in providing special reimbursement to the pediatric complex care clinic/program operated by their children's hospitals.[32]

EPSDT
This original core component of Medicaid may be a useful tool. While it is designed to assure children access to any medically necessary service, including reimbursement levels sufficient to enable that access, it is subject to interpretation regarding whether services are medically necessary and payment rates are high enough. Michigan has used EPSDT as the basis for obtaining state plan approval for a pediatric intensive feeding program with a bundled payment reimbursement methodology.

Summary
Please note that this is not an exhaustive list. There are other types of waivers and it is very difficult to definitively identify a limited set of SPA/waiver options, as attempted above, for a specific population or cluster of issues.

MCO/ACO Adapted Approaches

Contractual Requirements
Virtually any of the actions described above under Approaches for Service Delivery System/Reimbursement Innovation can be accomplished contractually through MCOs or other downstream structures where service delivery responsibility and financial risk is delegated. The contract with the downstream entity can require any service configuration or reimbursement method/amount that might be adopted by the Medicaid agency on a fee-for-service basis. For instance, the Medicaid agency could mandate each MCO to identify CMC (or a subset) and then require the MCO to use certain providers (perhaps specially approved by Title V) to serve them and/or that additional services and increased payments be provided.

MCO/ACO Independent Action
Any downstream organization could independently take the actions described under #2 if they have assumed a sufficient level of financial risk. Absent contractual requirements from the Medicaid agency, this requires negotiation/advocacy with each separate organization and the associated additional time and effort. While MCOs and ACOs are the most obvious organizations for this action, hospitals and others that can receive APMs also could have the capacity to implement these arrangements. A big disadvantage of this approach is that negotiation would have to occur with multiple organizations.

Special CMC Focused MCOs
Designate a specialty MCO or ACO to have enrollment limited to CMC or CYSHCN (e.g., the HSCSN MCO in Washington D.C. is contracted to serve only children who qualify for SSI).

This should translate to better access to providers prepared to serve this population, a broader array of covered services including more intensive care coordination, and reimbursement structures that are tailored to support such a specially designed service delivery system. While very attractive in many ways, this is a major undertaking with a multi-year planning and implementation time frame.

Different Scale Strategies for Sustainability and Replication

Developing a strategy for financially sustaining innovative service delivery methods for CMC is complicated for a number of reasons. First, there are a range of intervention designs across providers in different states as an emerging response to the growing number and complexity of CMC. There is no well-established evidence-based standard. Second, there is variance in state healthcare policy environments. Third, there is variance in the medical, geographic, socioeconomic, and cultural needs of CMC and their families and, more broadly, across and within states. Finally, there are the number and possible combination of Medicaid policy instruments that can form strategies.

On the positive side, this latter point highlights that there are many tools that exist (and have been growing over time) to improve Medicaid services to CMC. Many have been minimally employed and are waiting for their potential to be put to use. Collectively they offer great opportunity. Given the many strategic options available, the following will discuss approaches to achieve different levels of impact. For simplicity, three levels have been chosen for illustration. We will not revisit the Medicaid policy instruments in detail since they have already been described at length.

Ambition and scale are choices that are individual but also where odds of success are determined by state context.

Sustaining the Service Delivery Innovation in a Single Location – *most limited option*

Comprehensive pediatric complex care clinics are developing across the country and appear to be the most common service innovation for CMC. It is understandable that individual providers find that their immediate challenge is sustaining their pilot effort. The Medicaid policy instruments listed below can be used for these singular efforts.

It is important to note that Medicaid is built more for "systems of care" than singular, standalone models. That can increase the difficulty in getting your Medicaid agency's support but it is possible as some of the examples described earlier illustrate.

State Plan Amendment - CFR 431.615(c)(2)
An individual clinic or program could be uniquely recognized by the Title V program and Medicaid could authorize coverage and payment based on that designation.

State Plan Amendment for Targeted Case Management (TCM)

This approach can make CMC a defined TCM subpopulation for an individual qualifying provider. Since CMC is a broad term, it too would have to be defined to fit the specific interest here.

SPA via EPSDT Authority

The key is to develop criteria that will distinguish the targeted services from those that are standard coverages for the general population. There is considerable flexibility here since this is a broad principle.

Medicaid MCO/ACO Contract Requirements

For states that enroll a significant portion of the CMC population in MCOs or ACOs, Medicaid coverage of the pediatric complex care clinic intervention logically involves the MCO. The Medicaid agency has the discretion to require specific coverages and reimbursement methodologies from their contracted organizations simply applying the methods above downstream.

1115 Waiver

Some states have innovations that are more narrowly focused but where an 1115 waiver would be necessary. An example of these types of projects is one focused on lengthening the eligibility period for the NICU population along with more comprehensive services to support the child and family after they are discharged and transition back to the community.

Expanding the Innovation to a Statewide System – *mid-range option*

It seems fair to generalize that many innovative projects have the ambition to replicate their model at least throughout their state, if not beyond. Also, there are usually other institutions and clinicians with similar interests, awareness of need, and commitment as willing partners. This mid-range systems level will describe approaches to extend one model of comprehensive pediatric complex care services statewide. A statewide or even multi-region service delivery model for CMC is more in line with the Medicaid agency's inclination toward broader systems of care and may increase the likelihood of support and engagement.

Bring Single Location Strategies to Scale

The most obvious strategy is to expand the methods described above to statewide, or as close as to statewide as possible. This would involve building the service delivery capacity of other institutions/provider groups to meet the described requirements. The technique in every case should be identical to the strategies offered above, CFR 431.615(c)(2), TCM, EPSDT, MCO/ACO Contract Requirements and the 1115 waiver.

2703 SPAs

2703 SPAs can be targeted to sub-populations with health homes oriented to serve the special needs of that group. As an example, it appears permissible that a statewide system of comprehensive pediatric complex care clinics/programs for the most fragile children could be an innovation supported through one of these waivers. This brings advantageous federal financing support as described earlier.

Transformation to a Comprehensive System of Care for CMC and Their Families

Transformation, in a Medicaid policy context, includes expanding the number of CMC eligible for Medicaid, creating access to a developing comprehensive coordinated system of care designed to effectively serve all CMC and their families with reimbursement that supports the costs of that system.

The primary building blocks for that system are:

For Expanded Eligibility, the Family Opportunity Act (FOA)
This is the optimal policy instrument to achieve the most substantial expansion of Medicaid eligibility for CMC. It increases financial eligibility to 300% FPL for children who meet SSI criteria and does not disqualify those with commercial health insurance coverage.

With 1915 Waiver & TEFRA Complements
FOA adoption can be complemented by 1915(c), (i), (j), and (k) waivers and TEFRA State Plan Amendments primarily to provide HCBS. Most states have some combination of these in place already. An assessment of the adequacy of current waivers in place and the breadth of populations covered should determine the extent to which existing waivers leave gaps and unmet need. New waivers can be developed and/or enrollment caps increased.

For Service Delivery Transformation, the ACE Kids Act
This is the policy instrument with the broadest potential to optimize the service delivery system to be a highly effective system of care for CMC and their families. To repeat from above, this act is to "establish a State Medicaid option to provide coordinated care to children with complex medical conditions through health homes".[9] As such, it is a first order choice to design and build a service delivery system with pediatric complex care clinics as the foundation of the system. The fact that it calls for the development of a system of care for CMC, including the role of out-of-state providers, suggests the expansive potential both for codifying the roles of certain well-qualified providers and for the reimbursement structures that support those roles. This legislation contemplates an organized service delivery system for all CMC and thereby challenges states to build capacity to meet the full range of needs presented by different subsets of CMC. That level of comprehensiveness and integration may be challenging for health professionals and policymakers given how siloed American health systems have been, including those for CMC.

With a Range of Complements
Other service delivery enhancements could be combined with the ACE Kids Act. Nearly all of those sited in the mid-range level have the potential to serve as a complement in some way if useful.

For Target Population Alignment, an 1115 Waiver That Combines FOA and ACE Kids
The misalignment of the definitions of target populations in the ACE Kids Act and the Family Opportunity Act present an obvious opportunity for one type of 1115 proposal. The ACE Kids Act has a detailed definition of CMC in the legislation while the FOA requires an SSI level of function. An 1115 could propose combining the SSI level pediatric population targeted in the FOA with children meeting the ACE Kids more medically oriented CMC definition and make all Medicaid eligible up to 300% FPL within the FOA framework (i.e., make the ACE Kids Act defined CMC population Medicaid eligible up to 300% FPL with the FOA cost-sharing). All of

them could then be included in the ACE Kids service delivery system strategy developed by an individual state. To merit 1115 investment (time, effort, and potentially dollars), the proposal should incorporate a wide range of specialized care coordination and other support services to meet the varying needs of what would effectively be a relatively large population of CMC. APM type reimbursement methods are recommended since value-based methodologies are encouraged by CMS and can provide service delivery flexibility.

Financing Strategies

Funding is almost always a critical issue in moving policy forward. The response from policy makers to virtually any kind of proposal is typically a reflexive, "How are we going to pay for it?". This section will provide potential responses to that question. Costs in the context of your proposed initiative will be covered first followed by possible methods that can free up state and local general funds making them available to support your strategy.

The Costs of Your Initiative

Shifts in Utilization and Cost Offsets

While it is important to know the new costs of your proposed initiative, it is crucial to understand and be able to articulate that it also will change the utilization of other services resulting in cost offsets. Your proposal should not be narrowly treated as simply additional costs that must be financed with new revenue. The impact of service innovations is to shift utilization patterns, displacing some services with others. For example, there is growing evidence that pediatric complex care clinic services reduce inpatient hospital utilization and, on balance, result in reduced expenditures.[25,33–35] Whether a particular intervention results in overall savings may not have been determined but it is very likely to change the need for urgent, emergent, and acute care services. Also, just because the particulars of your service model have not been demonstrated to achieve cost savings doesn't mean that there isn't evidence that sufficiently similar interventions are cost effective. And in any case, the broad principle holds that new forms of service delivery change patterns of utilization.

Impacts on Other Human Services

Almost all health care cost effectiveness studies are limited to the healthcare domain. With the CMC population, there are often costs for other federal, state, and local programs. These costs merit consideration. With the employment of parents often impacted, limited earnings can require other forms of government support. Special education through the schools if usually in play. Improved outcomes and child functioning can reduce the intensity of need and services required from these other systems. It is important to point out these impacts and expand the horizons of policy makers.

Lifespan

Improvements in medical care has lengthened the lives of CMC. The advances in technology, therapies, drugs, surgery, and medical knowledge have all contributed to increased lifespans. CMC are frequently in need of substantial services throughout their lifetimes. Some level of

governmental support is virtually guaranteed indefinitely. Improved health and wellbeing of these children can have a marked impact on the level of future support and cost. This is one population where the only sensible approach is the long view, one that is absent in healthcare cost studies focused on relatively short timeframes.

Funding Strategies to Gain Support

There are aspects of federal, state, and local funding related to CMC services that are not universally understood. Below are three different, potentially advantageous ways in which funding can be incorporated into a broader policy package. There may be others, especially those that are unique to individual states, but the following are connected to CMC and likely applicable to all states.

Increase the Federal Medicaid Matching Rate (FMAP)

The funding enhancement most directly linked to possible CMC strategies is the increased FMAP for health homes provided through the ACE Kids Act and 2703 waivers. The enhanced matching rates are beneficial to states for the obvious reason that they reduce the state/local funding obligation to a manageably modest amount for a time period that gives the innovation an opportunity to prove its worth. As stated earlier, for health home services, the ACE Kids Act increases a state's FMAP by 15% for two quarters while 2703 waivers provide 90% FMAP for eight quarters.[9]

Opportunities to Convert Services to Medicaid Coverage and Partial Federal Financing

Services (in the broad sense of the term) to CMC that are exclusively funded by state and local expenditures can be explored for Medicaid coverage opportunities. As a matching program (i.e., federal Medicaid dollars support a state specific percentage of expenditures for covered services, normally starting at 50% and reaching as high as nearly 80%), the federal funding offsets that percentage of the total expenditure freeing up the previously committed state/local funding for other purposes. Almost any healthcare related service that is state/locally funded is a potential target for this financing strategy. Such a search can extend to a variety of state and local agencies as well as non-profit and provider centric organizations. Public health, education, and social services are good targets for exploration.

One fairly common example is where state or local (including philanthropic) funding supports care coordination in a setting with a substantial Medicaid population. New Medicaid coverage of care coordination in this setting could offset the state/local funding and make that savings available.

Financial Benefit of Medicaid Eligibility Expansion

It is important to point out the financial benefit to states from existing collateral Medicaid coverages which are incidental to any targeted eligibility expansion for CMC. This means, for example, that if eligibility is expanded through the FOA, current matching methodologies for services like school-based services for CMC in special education will increase in the amount of federal Medicaid funding earned. These newly eligible children will now receive "covered services" with the previously unrealized Medicaid dollars accruing to state government and/or public institutions.

Selling Points for Your Strategy

There are many benefits that should result from state implementation of one of these strategies. The most likely to have general applicability are listed below but this is by no means exhaustive. This can serve as a core set of the more obvious benefits and to stimulate your thinking.

Impact on CMC
These developing service delivery system improvements will have a significant impact on the health and wellbeing of children with medical complexity and their families. That is the first and foremost reason and should be enough all by itself. There is data to support this assertion.

Cost Effectiveness
A major consideration for payers is cost. As just pointed out in the previous section, new service models change patterns of utilization and aggregate costs. Further, there is evidence from a range of comprehensive pediatric complex care demonstrations that these service delivery models are cost effective.

Funding Strategies - Revenue Enhancement
See the discussion above under Funding Strategies to Gain Support.

Lifespan Cost Implications
See the discussion in the Financing Strategies section. The condensed version is that CMC are one population where the only sensible approach is the long view.

Family Health Maintenance & Stress Reduction
Pediatric complex care service delivery innovations reduce family stress and help maintain family health. The stress that a CMC places on families is in a category beyond what most can even imagine. At a minimum, this impacts employment reducing family income. The investment in family supports can provide relief that maintains family function and reduces the need for government services in the long run.

Organized Approach
There is recognition that our health care system is dysfunctional and ineffective in many ways. There is power in presenting a well-conceived and organized approach to healthcare for a very vulnerable population. There can be emphasis on how disorganized healthcare systems have particularly negative impacts on the health of CMC and their families.

Power in Family Experience
Bringing the human dimension to policymakers is amazingly effective in making the case for a more rational, comprehensive, and supportive system of healthcare. There is power in the realities that CMC and their families face.

COVID Spotlight
The COVID19 crisis shines a bright light on the additional challenges of persons with disabilities. The need for telehealth and a shortage of in-home caregivers are getting the most

attention. Bringing in this current challenge and the potential impact of your innovation on the attendant issues can be persuasive.

Summary

This is an exciting time with emerging innovations in services for CMC and their families. Comprehensive complex care targeted to this population holds great promise for better outcomes and overall wellbeing. Hopefully, this paper has brought an understanding to Medicaid policy tools and how they can be employed to improve and even transform service delivery. The aspiration is to contribute to the development of an organized, comprehensive, high-quality system of care for all CMC and their families.

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Author Contributions

Stephen Fitton conceived of the need for this content, developed the major ideas, and is the primary author of this document. Meg Comeau was a thought partner and helped to conceptualize and organize the document. Both authors read and approved the final manuscript.

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