

OPTIMIZING
HEALTH CARE FOR

CHILDREN WITH MEDICAL COMPLEXITY



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MEET RILEY



Ten-year-old Riley Cerabona is a frequent traveler to Boston Children's Hospital. Born with a rare, progressive disease called CLOVES, the level of coordinated, specialized care that Riley requires is not available at home in Maine, so she and her family have made countless trips up and down I-95. Since Riley was 3 months old, she's undergone 16 major surgeries and more than 40 MRIs to treat the overgrowth of benign lesions caused by the disease. The lesions have caused leg weakness and paralysis in her left arm, but these challenges haven't weakened her spirit. She is courageous, resilient, enthusiastic. She and her family are grateful her exceptional care enables her to do the things she loves: read, sing, act, spend time outside and play with her cats.

Daily life for children with medical complexity and their families isn't just complex when it comes to health care; every area of life is complex. Riley sees 14 different types of specialists; they are in addition to her primary pediatrician, her pharmacists, and her physical and occupational therapists. These are just the key medical professionals helping keep her physically healthy. Riley and her family also have outside support networks, accommodations at school, involvement in pediatric research as participants in a clinical trial, and time devoted to advocating for children with medical complexity. All the while, they also have to juggle three different types of payment—private insurance, Medicaid and self-pay—to ensure they get the home medical equipment and environmental modifications necessary to help Riley not only get by, but thrive.

OPTIMIZING HEALTH CARE FOR CHILDREN WITH MEDICAL COMPLEXITY

Photo by Louis E. Curtis Jr., Children's Medical Center Dallas, Dallas, TX



Children with medical complexity are a growing population. Approximately 3 million of the nation's 76 million children have medical complexity, and children with medical complexity are increasing at a rate of about 5 percent annually, outpacing the growth rate of children as a whole.

Children with medical complexity:

- Have diagnoses that are multiple and varied, from cerebral palsy to cystic fibrosis to congenital heart defects and childhood cancers
- Are under the continuous care of multiple pediatric specialists, often seeing a dozen or more physicians
- Require access to specialized care in pediatric centers of excellence
- Require additional services from within and outside of the health care system
- Travel regionally or even nationally for diagnostic and treatment services

CHILDREN WITH MEDICAL COMPLEXITY (APPROXIMATELY 6 PERCENT OF THE TOTAL NUMBER OF CHILDREN ON MEDICAID) REPRESENT NEARLY 40 PERCENT OF COSTS.

The current health care system has the medical training, knowledge and facilities to care for these children, but the processes around obtaining care and coordinating treatment are inefficient. Much of the time, discontinuity in these processes hurts quality and drives higher costs for everyone involved—patients, caregivers and payers. The variations in how each state supports this unique population also poses a significant barrier in sharing data and quality standards that can improve the care and outcomes for this small but high-cost population.

MEDICAID AND THE MEDICALLY COMPLEX

Children with medical complexity are concentrated in Medicaid and generate the highest expenses in the program:

- Approximately two-thirds of all children with medical complexity are covered by Medicaid
- These 2 million children (approximately 6 percent of the total number of children on Medicaid) represent nearly 40 percent of costs
- Medicaid is the largest payer for these children because the medical services they require often far exceed the traditional benefits and coverage levels commercial plans provide

Children's hospitals are the focal point of care for many of these patients, as pediatric specialists are often needed to provide expertise in treating their rare and complex clinical conditions. The expertise concentrated in children's hospitals serves children at local, regional and national levels to meet their complex needs.

Children with medical complexity have the highest needs and can be helped the most. They are also the population children's hospitals know the most about. It's vital to do what is best for these children. Long term, improving systems of care for children with medical complexity on Medicaid, taking care of them in a more efficient and effective way while reducing expenditures, is an important step in improving systems of care for broader populations of children.

NEED FOR A NATIONAL SOLUTION

Changing the system to provide and improve care, reduce costs and ensure adequate coverage for children with medical complexity who rely on Medicaid requires a national solution.

In addition to other challenges:

- Inconsistency across state Medicaid programs hinders care coordination, communication, provider access and continuity of care
- State-based Medicaid programs do not anticipate or adequately support care across state plans
- Rare diseases require large data sets to improve care, yet there is no national database for Medicaid claims data (like there is with Medicare)
- Current care models and today's fee-for-service payment systems are focused on payment volumes rather than on positive outcomes

Through medical home pilots and other initiatives, children's have advanced efforts to develop models for providing improved care coordination to these children. Although limited in number and size, small-scale medical home-type programs demonstrate it's possible to improve coordination of care, enhance the quality of life for families, reduce hospital utilization, and ultimately reduce costs.

This evidence suggests that broad-based implementation of similar care coordination programs across the U.S. would improve care quality and reduce the need for inpatient hospital care for this population as a whole, all while providing greater budget certainty and savings.

PROPOSAL TO IMPROVE CARE

Children's hospitals propose a realignment of optimal care models and Medicaid payment to create a national framework for children with medical complexity and their families supporting care coordination that is financially viable, that states can opt-into, and that will result in better care for these children.

Specifically, the proposal calls for the designation of national networks as the means by which children with medical complexity will receive all of the care they need in the most appropriate settings. These networks will:

- Improve care management, coordination and delivery
- Decrease unnecessary utilization and associated costs
- Improve quality of life for the patients and their families
- Reduce 10-year Medicaid spending by \$10 billion – \$15 billion

CHILDREN'S HOSPITALS PROPOSE A REALIGNMENT OF OPTIMAL CARE MODELS AND MEDICAID PAYMENT TO CREATE A NATIONAL FRAMEWORK FOR CHILDREN WITH MEDICAL COMPLEXITY AND THEIR FAMILIES TO IMPROVE CARE AND REDUCE COSTS.

This estimated cost savings for both federal and state Medicaid spending (2014-2023) is produced by decreasing the costs related to hospitalizations and emergency room visits while paying for the coordination of care for children with medical complexity.

The proposal calls for a national database (comparable to Medicare) to capture the care and costs of children with medical complexity. The health care system will benefit from a single resource of information (state-level databases on this relatively small subset of patients are insufficient to drive meaningful, evidence-based results) helping enable network care providers to continuously monitor and improve quality of care, advance best practices and set national standards for the care of these children.

Our research confirms these improved systems of care for children with medical complexity will be far superior for families compared to today's fragmented system. We encourage legislators, children's hospitals and related organizations to take an active interest in improving the care, delivery and cost of care for children with medical complexity. This proposal represents an important step to change care for these children and for all children.



MEET THE MEDICALLY COMPLEX

Photo by Daniel Hedden, Children's Specialized Hospital, Mountainside, NJ

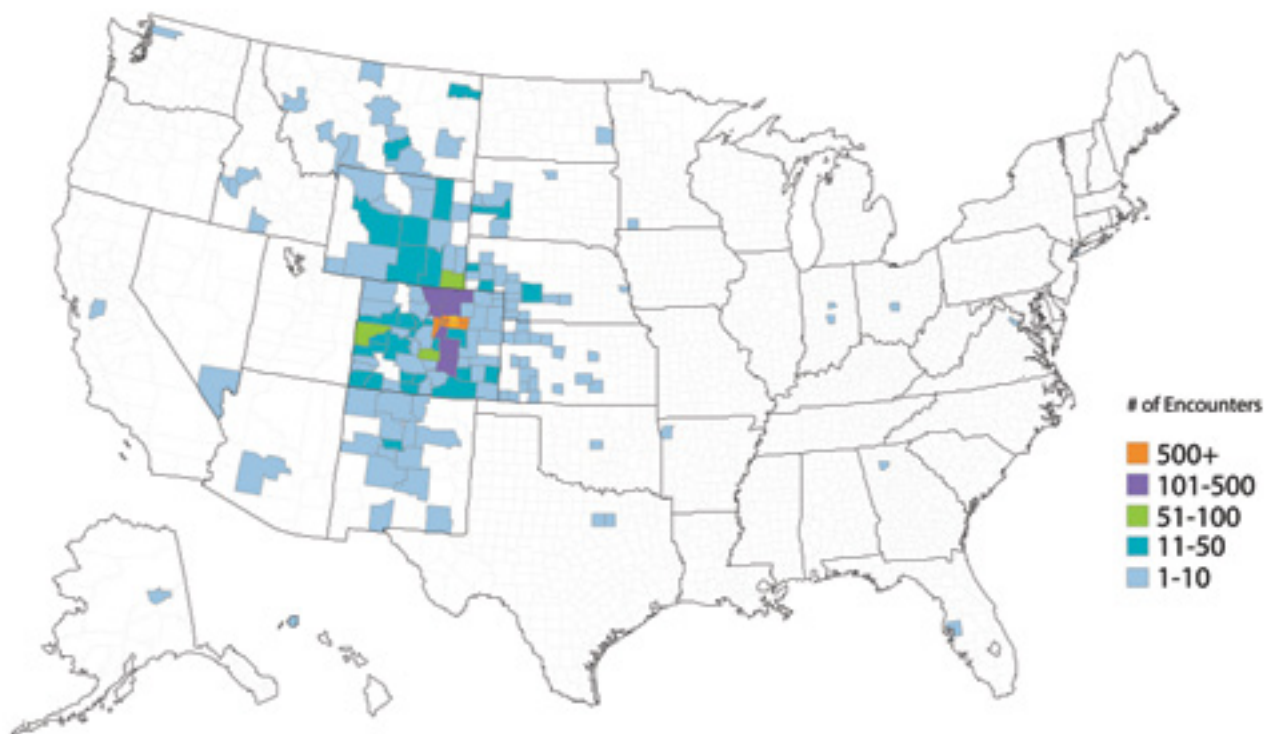


Children with medical complexity are children. They are not numbers, statistics or data points. Though numbers are essential to understanding the scope of the challenge, it is vital to remember that behind every number are children, each with a unique personality, smile, story, and family.

AMONG THE 33 MILLION CHILDREN IN MEDICAID, THE 2 MILLION WITH MEDICAL COMPLEXITY ACCRUE APPROXIMATELY 10 TIMES THE COSTS PER YEAR, ON AVERAGE, COMPARED TO OTHER CHILDREN IN MEDICAID.

Children with medical complexity need dramatically more health care services than their peers. Among the 33 million children in Medicaid, the 2 million with medical complexity accrue approximately 10 times the costs per year, on average, compared to other children in Medicaid. The medically complex pediatric population is very different clinically and socially from the adult population, and requires a different type of care coordination intervention. Their diagnoses and clinical conditions vary greatly. These children often have complex acute and chronic conditions; numerous comorbidities, a broad range of mental health and psychosocial needs, and can be technology-dependent (e.g., require a ventilator). Within the existing health care system, the care children with medical complexity receive is often fragmented, leading to long inpatient hospital stays, preventable hospital readmissions, and unnecessary emergency department visits.

**COUNTIES OF RESIDENCE FOR PATIENTS WITH MEDICAL COMPLEXITY ON MEDICAID
CHILDREN'S HOSPITAL COLORADO, DENVER, CO**



Data Source: 2012 Discharges, Pediatric Health Information System database

The services children with medical complexity need are so specialized that families often have to travel long distances to receive the services they need, frequently crossing state lines. The concentration of teams of specialists at large children's hospitals underscores the regional nature of care for high acuity conditions. The map above shows the home counties of patients seen at Children's Hospital of Colorado. All patients represented are children with medical complexity enrolled in Medicaid.

Due to improvements in medical treatments for both chronic and severe pediatric conditions, as well as increased survival rates for neonatal intensive care unit (NICU) patients, the population of children with medical complexity has increased substantially. As this population has grown, children's hospitals are increasingly the only places with the breadth of pediatric specialists and subspecialists, equipment, and other resources often required to treat the rare and complex clinical conditions of these children.

THE SERVICES CHILDREN WITH MEDICAL COMPLEXITY NEED ARE SO SPECIALIZED THAT FAMILIES OFTEN HAVE TO TRAVEL LONG DISTANCES TO RECEIVE THE SERVICES THEY NEED, FREQUENTLY CROSSING STATE LINES.

Over the past several years, children's hospitals have observed substantial growth in the number of and spending related to children with medical complexity. In addition, chronic and complex conditions generally have consumed a larger proportion of inpatient pediatric resource use. Later in life, these children will require guided transition to the adult health care world. And with all of these things come mental health and psychiatric challenges, not just for these children, but for their families who function as round-the-clock caregivers for months, years or even lifetimes.

DEFINING MEDICAL COMPLEXITY

Clinicians, researchers, and policymakers have developed numerous different ways to define the population of children with the greatest clinical, physical, and psychosocial needs. Although there is not yet a standard definition of medical complexity, four cardinal domains characterize these patients:

1. Chronic, severe health conditions
2. Substantial health service needs
3. Major functional limitation
4. High health care resource utilization

Children with medical complexity can be defined by using 3M Clinical Risk Groups (CRGs), which rely on utilization data and ICD-9 codes to classify individuals into hierarchical groups of increasing complexity and severity.

CRGs were first released in 2000 and are updated annually to improve the classification system. Refinements scheduled for 2014 should continue to enhance the system's effectiveness for identifying complex populations and children with medically complex conditions; tracking and managing services; targeting care coordination; linking to measures of quality and satisfaction; and use with various kinds of payment. States like New York and Massachusetts, among others, already have CRGs in wide-spread use for risk adjustment and quality assessment.

MEDICAL COMPLEXITY					
	NON-CHRONIC (CRGs 1, 2)	EPISODIC CHRONIC (CRGs 3, 4)	LIFELONG CHRONIC (CRG 5*)	COMPLEX CHRONIC (CRGs 6, 7, 9)	MALIGNANCIES (CRG 8)
Brief Description	<ul style="list-style-type: none"> Acute conditions that will not last one year 	<ul style="list-style-type: none"> Chronic conditions that will last one year and are likely to be episodic in manifestation Potentially curable with adequate treatment Not likely to last into adulthood 	<ul style="list-style-type: none"> More severe primary condition in one body system that is more likely to cause significant long-lasting health impairment 	<ul style="list-style-type: none"> Significant chronic condition in two or more body systems or Progressive or life limiting chronic conditions or Conditions requiring a dependency on technology 	<ul style="list-style-type: none"> Malignancies requiring active treatment
Example Conditions	Fracture, pneumonia, appendicitis, trauma	Asthma, depression, conduct disorders	Type 1 diabetes, congenital heart disease	A child with diabetes, encephalopathy and chronic pulmonary disease. Down syndrome, cerebral palsy, cystic fibrosis	Leukemia, bone tumors, brain tumors

*CRG Category 5 is further broken into two subcategories by the Children's Hospital Association - 5a and 5b. The definition of Children with Medical Complexity includes 5b - Single Dominant Chronic Disease, such as those with Sickle Cell Disease or Congenital Heart Disease.

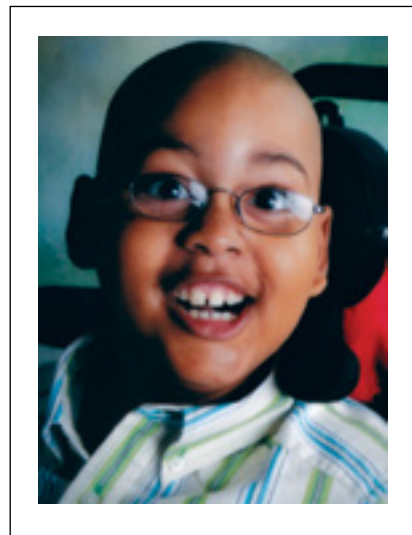
Within the CRG system, each patient is classified into one of nine core health status groups. The groups range from healthy children to children with catastrophic chronic conditions associated with high morbidity and mortality. (see table above)

Analysis suggests that children with medical complexity are a distinct population and should be considered separately from broader guidelines being discussed which outline a population of children with special health care needs (CSHCN), a grouping that includes patients with single, widespread chronic diagnoses like asthma, hypertension or obesity. All children with medical complexity count within a CSHCN population, but these children have such intense health care needs that even systems well designed for the larger population of CSHCN may be inadequate or inefficient for children with medical complexity.

LITERATURE REVIEW

Released in June 2013, an independent literature review, *The Landscape of Medical Care for Children with Medical Complexity*, outlines the various methodologies that have been used to define children with medical complexity, discusses relative merits of these methodologies, and looks at range of published work that helps contextualize perceived best practices for caring for this population. This report is available online at www.childrenshospitals.org/cmclitreview.

PATIENT SPOTLIGHTS



HUNTER L. HENRY | At 7 months old, Hunter Henry was diagnosed with static encephalopathy, a form of permanent brain damage. Today, at age 11, his diagnosis also includes spastic quadriplegia, cerebral palsy, mental retardation, acid reflux and chronic respiratory disease. After seven surgeries and lots of therapy, Hunter has finally stabilized. Despite his challenges, Hunter remains handsome and sweet, with a smile that can inspire and encourage those around him.

A Maryland native, Hunter has received the therapy and the necessary equipment he needs to make daily living easier at The HSC Pediatric Center in Washington, DC. He and his family have been blessed to have Maryland Medicaid REM (Rare and Expensive Case Management) insurance. Without Medicaid, Hunter's complex medical needs would not have been met and he wouldn't be able to spend his free time playing with his best friend and sister, Halley.

AUDRINA CARDENAS | A routine ultrasound 16 weeks into Ashley Cardenas' pregnancy uncovered a problem: part of her unborn daughter's heart was forming outside of the chest. Ashley was given three options: termination, comfort care, or a risky post-delivery surgery.

Less than 1 in 100,000 babies are born with ectopia cordis, a rare congenital malformation where the heart is located either partially or totally outside the chest; 90 percent are either stillborn or die within the first three days of life.

On Oct. 16, 2012—one day after Audrina's birth—surgeons at Texas Children's Hospital saved Audrina's life during a miraculous six-hour open heart surgery where they reconstructed her chest cavity to make space for the one-third of her heart that was outside of her body. Despite Audrina's misplaced heart, she was born with no other additional stressors on her heart. After a successful surgery and three months in the intensive care unit, Audrina got to go home for the first time.

Although her future prognosis is uncertain, she is currently thriving, making progress each day. Doctors expect she will undergo more surgeries, including one to form a sternum. Until then, Audrina wears a special protective shield over her chest to keep her safe.

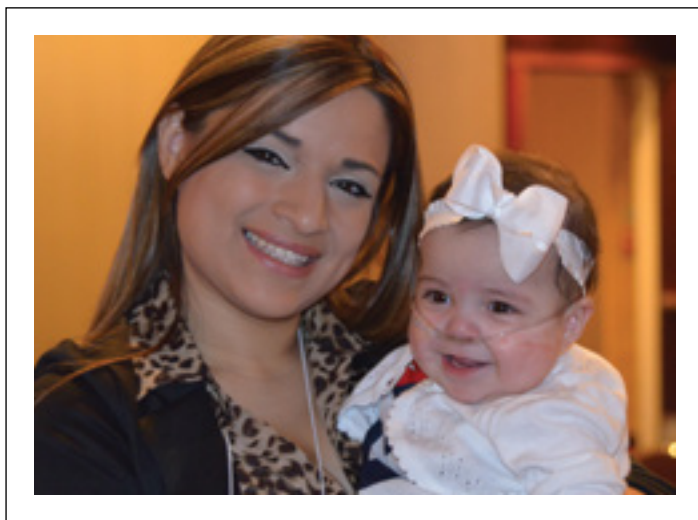




Photo by Phyllis Karen Brown, University of California Davis Children's Hospital, Sacramento, CA

MEDICAID IS A FEDERAL-STATE PARTNERSHIP WITH EACH STATE ADMINISTERING ITS PROGRAM DIFFERENTLY. THIS COMPLICATES MEETING THE HEALTH CARE NEEDS OF THESE CHILDREN WITH MEDICAL COMPLEXITY.

CHALLENGES TO CHANGING CARE

Photo by Katie Burckhalter, Mercy Children's Hospital, St. Louis, MO



A FRAGMENTED SYSTEM

While Medicaid offers some comprehensive health care benefits for children with medical complexity, these children, their families and their providers grapple with significant problems across our heavily state-based and decentralized Medicaid program.

Medicaid is a federal-state partnership with each state administering its program differently. Given the complexity of their conditions, families of children with medical complexity routinely travel over longer distances and across state lines to see their pediatric specialists. Inconsistency across state Medicaid programs hinders care coordination, communication and provider access that is essential for advancing the quality of care for these children.

CHILDREN WITH MEDICAL COMPLEXITY ALSO NEED A SYSTEM THAT ENABLES LONG-TERM CONTINUITY OF CARE WITHIN THE SAME NETWORK, MAKING IT POSSIBLE FOR CHILDREN AND THEIR FAMILIES TO SUSTAIN A RELATIONSHIP WITH THEIR CARE PROVIDERS TO COORDINATE CARE NEEDS.

DATA STANDARDS

Children with medical complexity require care from multiple providers who do not have the benefit of national quality standards and data to support necessary care and cost improvements. Unlike Medicare where national data exist to improve care for adults, state-based Medicaid data are not available in standard, accessible formats. In many instances, there may only be a handful of children in a state with a particular disease or condition; the creation of a national linked claims database is necessary to advance care for these children.

OPTIMAL OUTCOMES

One of the greatest challenges to the Medicaid system is that payments are based on patient volumes, not on positive outcomes. Delivery of best practice care, driven by data, needs to be accompanied by a payment model supporting best practice care.

The reimbursement system needs to align incentives to support care provision in the most cost-effective setting. A refined Medicaid reimbursement system would allow the care provider to decide what treatment a child needs while providing the care coordination that results in positive outcomes.

CONTINUITY OF CARE

Children with medical complexity also need a system that enables long-term continuity of care within the same network, making it possible for children and their families to sustain a relationship with their care providers to coordinate care needs over years or even decades. Continuity of care is vital, whether families are covered by Medicaid managed care, commercial insurance or by the new health insurance exchanges. However, as families move into health exchanges for their insurance and wish to, or must, change plans, there is increased potential for disruption and discontinuity of their care patterns.

NATIONAL CONTEXT

More than 70 percent of all Medicaid enrollees in the U.S. are in some type of managed care plan, so it's important to envision a plan for transforming care for children with medical complexity that takes into account the way managed care plans currently cover children.

Historically, children with medical complexity have not been enrolled in managed care organizations (MCOs) which focus on primary and preventive care as well as minimizing costs. MCOs do not generally cover children with medical complexity due to their high acuity-related needs including multi-specialty care.

The growing managed care environment does not factor in the additional services needed to provide appropriate care to a high acuity population with a wide array of critical needs like children with medical complexity. Managed care is historically a price-sensitive industry that leverages the lowest cost provider, and this approach may leave out the option of appropriate care through a children's hospital or pediatric subspecialist.

NEED FOR CONSENSUS

Today's challenges in Medicaid for children with medical complexity are many, ranging from the fragmented state-by-state systems to federal and state budget cuts to a payment model not aligned to improve delivery of care, all threatening the program's fundamental viability. The nation has a choice to either strand children with medical complexity in this flawed arrangement or build consensus to advance a better system.



SOLUTIONS FOR CHILDREN WITH MEDICAL COMPLEXITY

Photo by Ben Van Hook, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE



Many Children's hospitals have implemented a "medical home" model for some subset of their patient population. These pilot programs offer many of the best examples of how a population can benefit from streamlined, coordinated care.

A "PATIENT-CENTERED MEDICAL HOME" ISN'T A PHYSICAL FACILITY, IT'S A CONCEPT FOR FULLY PATIENT-CENTERED, MULTIDISCIPLINARY CARE.

The concept of a "medical home" has been around since the 1960s, but the implementation has evolved far beyond the original idea. The current iteration, usually referred to as a "patient-centered medical home" isn't a physical facility, it's a concept for fully patient-centered, multidisciplinary care. A medical home brings together all elements of a patient's care—physicians, clinical staff, care coordinators, health educators, administrative team members, etc.—and streamlines them into one or two consistent, ongoing points of contact for a patient family.

The medical home also serves to help educate and support family members to develop their capacity to be key members of the care team in decision making, care planning and care coordination to meet the various care needs of their children over time.

SHIFTING THE BULK OF THE WORK OF COORDINATING CARE FOR A CHILD OFF OF THE CHILD'S PARENTS AND ONTO THE MEDICAL HOME CAN ALSO GIVE PARENTS MORE TIME TO BE MORE ENGAGED IN THEIR CHILD'S CARE, AND BE MORE ABLE TO ADDRESS AREAS OF LIFE BEYOND MEDICAL TREATMENT.

The medical home takes on leadership in coordination of care, and does so from a holistic perspective, when possible even keeping in context social and cultural concerns in addition to medical needs. Shifting the bulk of the work of coordinating care for a child off of the child's parents and onto the medical home can also give parents more time to be more engaged in their child's care, and be more able to address areas of life beyond medical treatment.

ELEMENTS OF A MEDICAL HOME

Ideally, best practices for delivering clinical care to children with medical complexity should address the four key domains characterizing these children. That is, care should:

1. Mitigate the severity of the child's chronic health conditions
2. Effectively meet the needs of the child and family in a timely manner
3. Maximize the child's functional abilities
4. Minimize avoidable hospitalizations as well as other ineffective and/or unnecessary use of health resources

The medical home that meets these goals has at its core a care team, a care plan for every patient and shared communications that make it accessible, continuous, comprehensive, coordinated, compassionate, culturally competent, and family-centered. Although valid and meaningful in theory, operationalizing these care attributes into discrete, effective care processes that can be implemented and measured is challenging.

PATIENT CARE BENEFITS

A medical home minimizes the risk that a necessary treatment will be delayed or overlooked. It increases the chances that the appropriate level of expertise and staffing will be used to address each of a child's medical problems, and it reduces the risk of miscommunication among the often 10 or 20 different health care providers and allied professionals that can be involved in care of a single child with medical complexity.

ACCESSIBLE CARE

Many children with medical complexity have a high likelihood of experiencing problems (e.g., acute illnesses, technology malfunction, etc.) that, if not addressed in a timely manner, may lead to a rapid decline in their health. It is essential that they have access to providers with specialized pediatric training to care for their unique needs. It is very important, then, that these children have access to an ambulatory care site that can urgently address their health care needs in person or over the phone. It is hypothesized that the absence of such a site contributes to increased emergency department visits, hospitalizations, and readmissions. Providing accessible urgent care for children with medical complexity is often not easy or quick. It can sometimes take hours to sort through an acute health problem in one of these children, but this is still far superior to the alternatives.

COORDINATED CARE

Many children with medical complexity have chronic conditions that affect multiple organ systems creating a reliance on multiple specialty pediatricians to independently treat each system. Because body systems, by design, are integrated, instituting a care plan to treat one body system may adversely impact another system. As a result, it is critical for medical decisions to be coordinated among the members of a child's health care team. Care planning should be actively discussed with the family and providers within the context of all health problems and issues. This is not a simple task, especially when the child has several different clinical providers and when there is discordance among team members about a particular medical decision.

COMPREHENSIVE CARE

It is also very important for at least one health care provider to approach the child comprehensively; that is, the provider systematically assesses each problem and need in the context of the child's overall health and well-being. The type of provider (e.g., physician, nurse, case manager) performing these assessments varies by program and practice. This comprehensive assessment is necessary to develop over-arching goals of health and to create complete, proactive plans of care designed to keep the child as healthy as possible. This assessment often identifies unmet needs and neglected health problems that require attention. With extensive knowledge of the child's situation, this provider can anticipate and address new issues. Without proactive plans, children with medical complexity will continue to experience crisis-driven management which often leads to over-treatment and overuse of emergency and hospital care.

ASSESSING MEDICAL HOME MODELS

Interviews conducted with seven children's hospitals looked at trends in care coordination for children with medical complexity. The variety of hospitals and programs highlights the range of creative, data-driven ways in which children's hospitals are working to meet the needs of patients locally.

Organizations interviewed included: Arkansas Children's Hospital, Children's Mercy Hospitals and Clinics, Cincinnati Children's Hospital Medical Center, Ann & Robert H. Lurie Children's Hospital of Chicago, Seattle Children's, Texas Children's Hospital and Children's Hospital of Wisconsin.

Their hospital programs to coordinate care for children with medical complexity range in size and maturity (or level of development), with most programs having between 200 and 600 patients enrolled at a time. Thus, most programs serve a small share of the medically complex pediatric population. Ann & Robert H. Lurie Children's Hospital of Chicago, at one end of the continuum, is the only hospital with a large scale program (~10,500), while Children's Mercy Hospitals and Clinics does not have a formal, comprehensive care coordination program in place and is in the process of creating one.

- Program elements in common:
 - A multidisciplinary care team of physicians, registered nurses/nurse practitioners, care coordinators, social workers, dietitians, medical assistants
 - A dedicated case manager or single point of contact for each patient and the patient’s physicians and family
 - 24/7 access to a clinician by phone
 - Coordination with community resources, including social support services (sometimes referred to as a “medical neighborhood”)
 - Medication reconciliation
- The hospitals noted that the medically complex pediatric population is very different clinically and socially from the adult population, and requires a different type of care coordination intervention. The diagnoses and clinical conditions of children with medical complexity vary greatly within each program, and many have unique combinations of diseases, developmental disabilities, and/or are technology-dependent. Mental health and psychosocial needs are very prevalent and must to be taken into account in the care management plan for these patients.
- Typically, the majority of patients enrolled in these programs are enrolled in Medicaid
- The transition into the school system at age 3 and the transition from childhood to adulthood for patients with medical complexity are difficult
- For the states that provide reimbursement for care coordination (e.g., Texas and Wisconsin), the level of reimbursement is insufficient to cover the costs of the services

No hospital or care coordination program has developed a risk-based or shared savings-type payment model that covers the cost of administering the program. All programs to date are funded by the parent hospital or other sources of funding (such as external fundraising). However, to make these programs financially sustainable to support the medical home, an integrated financial model is key.

ADDITIONAL RESOURCES

Hospital interviews, case studies and other resources to deepen your understanding of children with medical complexity, the challenges they face, and the ideas being implemented to transform their care are available at: www.childrenshospitals.org/cmcresearch.

CHILDREN'S HOSPITALS HAVE WORKED TO DEVELOP A FEDERAL LEGISLATIVE PROPOSAL FOR THE DESIGNATION OF NATIONAL NETWORKS AS THE MEANS BY WHICH CHILDREN WITH MEDICAL COMPLEXITY WILL RECEIVE ALL OF THE CARE THEY NEED IN THE MOST APPROPRIATE SETTINGS.

A FOUNDATION FOR REFORM

Photo by Ben Van Hook, Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE



Over the past two years, children's hospitals have worked to develop a national legislative proposal focused on realigning optimal care with Medicaid payment models to improve care for children with medical complexity covered by Medicaid. This year, a group of more than 50 hospitals has refined and enhanced the proposal, building on new data and analytic findings.

Specifically, the proposal calls for the designation of national networks as the means by which children with medical complexity will receive all of the care they need in the most appropriate settings. National designation is intended to ensure minimum network adequacy requirements for the ongoing care of children with medical complexity regardless of their state of residency. These networks, anchored by children's hospitals, will improve care management, decrease unnecessary expense and utilization, and reduce hospitalizations and associated costs. By design, these networks will ensure care is better coordinated and delivered, improving quality of life for the patients and their families. Importantly, these networks could reduce 10-year (2014-2023) Medicaid spending (both federal and state) by \$10 billion – \$15 billion, depending on the level of state engagement and the efficiency of implementation—an approximate 2 percent reduction to Medicaid spending for children with medical complexity.

THE PROPOSAL

THE PROPOSAL OUTLINES SOLUTIONS IN FIVE MAJOR AREAS:

NATIONAL DESIGNATED NETWORKS Nationally designating networks anchored by children's hospitals will ensure adequacy of, and access to, specialized programs, support services and medical homes for children with medical complexity. Networks will be designated by the Centers for Medicare & Medicaid Services (CMS) based on their ability to accept accountability and meet network adequacy and delivery criteria.

COORDINATION OF CARE Nationally designated networks will provide care coordination to children with medical complexity and their families. Families will have choices and roles in the care their children receive.

INFORMATION AGGREGATION Networks would participate in the development of shared clinical and financial information supporting the definition of benchmarks, best practices and standards necessary to continuously improve quality and reduce costs. It is critical data be collected at the national level due to the small size of this population.

ACCOUNTABLE CARE Networks will be financially and clinically accountable to establish a clear incentive to reduce costs. Risk assumptions will be phased in over the initial two-years as the data are collected and assessed to actuarially inform a viable risk-based payment methodology.

SHARED INCENTIVES Ultimately, the objective is to align incentives between the states and network participants. Shared savings through shared risk would provide networks a potential funding source for reinvestment in the medical home care coordination infrastructure supporting quality and cost management improvements.

The potential cost saving is produced by decreasing the costs related to hospitalizations and emergency department visits while paying for the coordination of care for children with medical complexity.

In addition, because the proposal calls for a national database (comparable to Medicare) to capture the care and costs of children with medical complexity, the health care system will benefit from a single resource of information. Children with medical complexity often have such rare diseases and conditions that it's challenging or impossible to have a statistically meaningful study size without national data. With national data, network care providers will be able to continuously monitor and improve the quality of care, advance best practices and set national standards for the care of these children.

Ideally every state will elect to opt into this program to ensure the nation's children with medical complexity benefit, and the system realizes its full potential. Similarly, pediatric providers and provider communities across the country will determine their interest in creating, offering or participating in a network for children with medical complexity within their states and regions.

RESEARCH SUPPORTING REFORM

Dobson DaVanzo & Associates, LLC, (Dobson | DaVanzo) estimated the impact of creating a new payment and delivery system for children with medical complexity on Medicaid federal and state spending over a 10-year period (2014–2023). The research suggests the formation of nationally designated pediatric networks could be established based on a legislative proposal developed by children’s hospitals. As noted previously, the goal of the legislative proposal is to more effectively address the complex needs of these patients by enhancing care coordination, which necessarily involves care outside of the hospital.

METHODS IN BRIEF

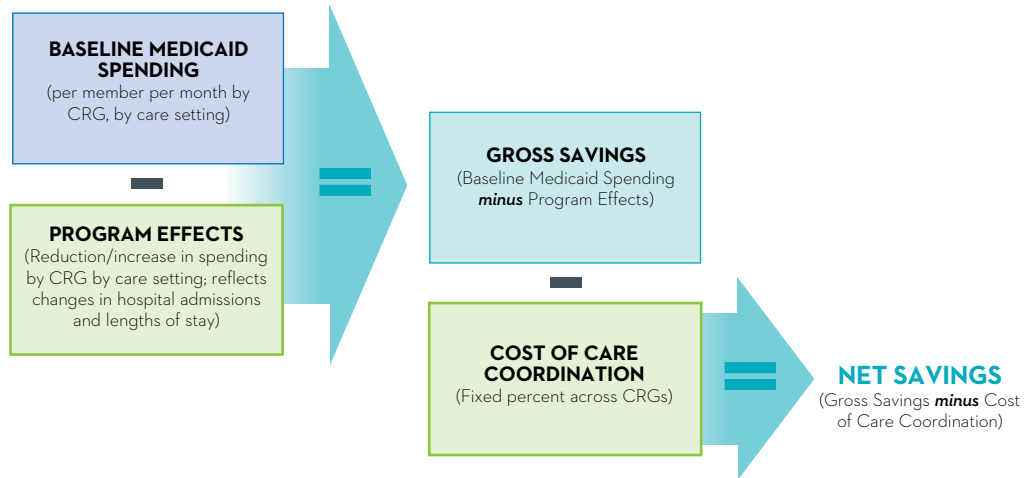
To estimate the financial impact on the Medicaid program of implementing nationally designated pediatric networks for children with medical complexity, Dobson | DaVanzo projected baseline Medicaid enrollment and spending for medically complex children using Truven Health Analytics’ data analyses of a 12-state sample of Medicaid claims from 2009 to 2011, Medicaid summary statistics, and other secondary data analyses. Based on published literature, Dobson | DaVanzo estimated the difference between Medicaid spending for children with medical complexity at baseline and Medicaid spending for these children under nationally designated pediatric networks (“gross savings”), varying spending across different sites of service and categories of children with medical complexity.

Development of the savings estimation model was informed by a series of key informant interviews with clinical and administrative representatives of several children’s hospitals currently operating care coordination programs. Furthermore, all of the model assumptions were reviewed by two advisory bodies organized by the Children’s Hospital Association—the Finance Work Group and the Medical Home Network Team—both including clinicians with expertise in children with medical complexity and children’s hospital administrators. Dobson | DaVanzo then subtracted the costs to the program to improve care coordination for these patients to estimate the “net savings” to the Medicaid program.

SAVINGS

Dobson | DaVanzo estimates that, under a range of assumptions, a program to create nationally designated pediatric networks for children with medical complexity in the Medicaid program could reduce 10-year (2014–2023) Medicaid spending (both federal and state) by \$10 billion – \$15 billion if implemented as a voluntary state opt-in policy.

CONCEPTUAL FRAMEWORK FOR SAVINGS ESTIMATION MODE, 2013-2024



If children's hospitals are able to invest in the infrastructure to improve care coordination rather than increase the number of hospital beds and capacity for inpatient care, the Medicaid program could see further reductions in hospital spending over the long term. Such an outcome will require hospitals to change their business models to focus on maintaining patient health status in the community and reducing admissions or length of stay, but the financial incentives put forth in the proposal are designed to lead in this direction.

A handful of key assumptions shape the data:

- Congressional Budget Office (CBO) scoring window 2014 to 2023
- Children with medical complexity population includes all Medicaid ages 0 – 18
- Growth rate of the population (2011 to 2013, 2014 to 2023)
5 percent annually (~ historical Medicaid plus 1 percent)
- Phase-in of program savings (2014 to 2017, sustained after year 4)
Year 1 – 10 percent, Year 2 – 30 percent, Year 3 – 60 percent,
Year 4 – 100 percent
- Care coordination costs (2014 to 2023)
9 percent of total per member per month (weighted average of
approximately \$150 per member per month)
- Phase-in of care coordination costs (2014 to 2016, 2017 to 2023)
Year 1 – 150 percent, Year 2 – 125 percent, Year 3 – 100 percent

WEIGHTED AVERAGE PROGRAM IMPACT BY CARE SETTING

CARE SETTING	WEIGHTED AVERAGE PROGRAM UTILIZATION IMPACT
Inpatient Facility	-40%
Outpatient Facility Total	10%
Emergency Room	-20%
Primary Care Provider	30%
Prescription Drugs	10%

Source: Dobson | DaVanzo analysis of published literature.

MEET LILY

Most children with medical complexity rely on Medicaid for all or part of their health coverage. Yet Medicaid's variability from state to state, its lack of national pediatric quality measures, its dearth of national data for evaluation and improvement, and its payment system—which is not aligned to improve care delivery—leave children with medical complexity and their families to navigate a highly fragmented system on their own. This vulnerable population will be put at risk as more and more children are moved into managed care which does not generally factor in the additional services needed to provide appropriate care to children with medical complexity.



LILY'S STORY

Lily Putney was born happy, healthy, and developmentally normal in 1998 in Yokosuka, Japan, where her father Anthony was stationed with the U.S. Navy. Everything changed when Lily was 15 months old; an ear infection spun out of control into life threatening “presumed viral encephalitis” (an inflammation of the brain), which led to a seizure disorder, developmental delays and cerebral palsy. She was hospitalized for 5 months.

The Navy gave Anthony a choice to move to be closer to the care Lily needed, so the Putneys ended up in southern California, near Children's Hospital Los Angeles.

According to Anthony, care in the military hospital was very good, and they worked hard to figure out what was going on. But the care in the children's hospital made a big difference. That was 12 years ago and since then Lily has been treated in children's hospitals throughout the country as her father's military service kept the family on the move. Originally an air traffic controller, Anthony changed careers within the Navy to become a nurse to be able to better care for Lily.

“Kids can get sick much faster than adults; they definitely need a group of specialists who focus on kid's needs on a daily basis,” Anthony says. “What happened to us can happen to anybody. If what happened to us happened to any other family, they would need the same specialized care we received, and are receiving now.”



Lily's parents mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life.

After more than a decade of frequent moves, the Putneys settled back in their hometown of Egg Harbor Township, NJ, in 2010, where Lily has enjoyed the therapeutic services of Children's Specialized Hospital. But even geographic stability doesn't make things easy for the family.

Lily receives both TRICARE (the health care program for active duty military, retirees, their families and survivors) and Medicaid, to supplement services TRICARE doesn't cover. There have been challenges with Medicaid, especially crossing state borders to receive specialty care outside of New Jersey, in Philadelphia for example. Recently New Jersey privatized its Medicaid program instructing enrollees to select an HMO. According to Anthony, "It's difficult when you have a child that sees so many different specialists and so many different hospitals or different organizations, trying to coordinate all of that care when some of them may not take your HMO."

Now 15, Lily has many physical and medical challenges; she is non-verbal and non-ambulatory, but continues to improve her ability to communicate.

FRAMEWORK TO MEET OUR OBLIGATIONS

Amy Mansue, president and CEO of Children's Specialized Hospital, where Lily receives therapy, points out that saving Lily's life was not the hard part. "Making sure Lily has a quality of life is the part that we all have an obligation to fulfill."

After more than two years of research and work to broaden awareness of the needs of these children, children's hospitals are now proposing national legislation to ensure children like Lily, Audrina, Hunter and Riley receive high quality, coordinated care from a collaborative team of specialists committed to optimizing patient care and the families' experience in the health care system. The proposed framework will work better for families, the children's hospitals anchoring the networks, the myriad of pediatric providers in the networks and for Medicaid.



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