

## Proceedings

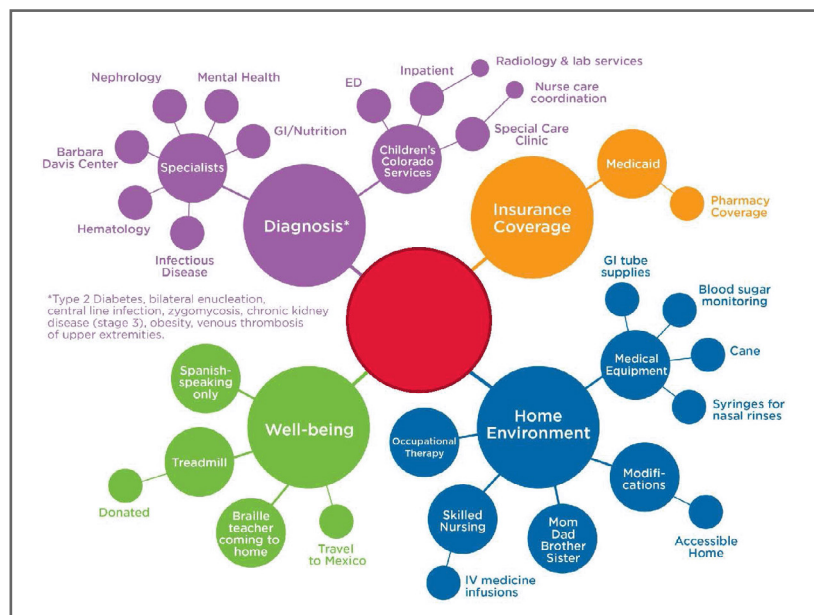
# 2015 Symposium:

## Designing Systems That Work for Children with Complex Health Care Needs

December 7-8, 2015

National Academy of Sciences Building

Washington, D.C.



Prepared by Steve Olson

On December 7-8, 2015, the Lucile Packard Foundation for Children's Health organized a national symposium entitled, "Designing Systems That Work for Children with Complex Health Needs." Children with complex health care needs are a sentinel population for shortcomings in the organization and financing of children's health care in the U.S. This invitational symposium identified and discussed issues within the general child health care system that have particular salience for the care of children with complex health problems. It provided a forum to learn from those making progress on these issues as well as those working in adult health care and health policy. Participants engaged in dialogue to identify solutions to the issues, make recommendations for adoptions of those solutions in practice, programs, and policy.

Please visit [lpfch.org/symposium/webcast](http://lpfch.org/symposium/webcast) to find recordings of each session of the symposium, along with presentation slides.

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## Introduction and Overview

“Forget who I am,” said Rylin Rodgers, a mother with two children who have complex health needs. “Think about the hundreds, thousands, tens of thousands of families I represent.... It is for those families—and for the new children born each day with a complex health care need—that our work together matters most.”

A few hours after the birth of her son, Matthew, 18 years ago, Rodgers learned that she had a child with special health care needs. “I knew at that moment, if he lived for more than a few hours, that my family and I were jumping into a whole new world.” From her research in the days and weeks that followed, she discovered that her son did not need to spend his life in an institution. She read about Katie Beckett, a child who was living with health complexity at a time when children with medical complexity generally were forced to live in hospitals and institutional settings because Medicaid did not cover their care at home. “Katie's family fought for, and won, changes to the Medicaid program that allowed for her and children like her to play, grow, and learn at home, where they belong. I learned, by reading about Katie's family, that I would be able to take Matthew home along with his very heavy load of medical equipment. I also learned, by their example, that if I ran into a problem with the systems and services that were in place to support him, I too could change federal law.”

In the days before health care reform, her family became uninsured after reaching their lifetime limit while Matthew was still in the neonatal intensive care unit. He was waitlisted for Medicaid wavers, and the family's medical debt accumulated. Three years later, Rodgers' daughter, Laura, was born with the same unnamed condition. “Now I had two children with special health care needs and no named diagnosis.” Not until several years later did they get a diagnosis: mitochondrial myopathy, which can cause nerve and muscle damage throughout the body.

Even with a diagnosis, the path for her family was not clear. Her children would need a lifetime of ongoing and complicated care, said Rodgers, but care systems, support systems, and financing are constantly in flux. Therefore, care coordination that moves with the child and family across the life course has been an elusive but constant goal for her family. Good care coordination must support care following a new diagnosis, evolve during transitions, guide different teams during crises, incorporate mental health, and empower children to self-manage their own care as they get older. It can do so, said Rodgers, but only if it is family-centered, because families “are the sole constant in their child's life.”

Limits on hospital stays, home nursing support, and providers mean that families are managing complex health care needs out of the hospital and with minimal support, Rodgers observed. She and her family live in rural Indiana with no reliable access to home care and an hour-long drive to needed sources of health care. Schools, 4-H clubs, churches, and extracurricular activity providers have taken on aspects of their care, as have the children themselves. Such work can be physically and emotionally exhausting, said Rodgers, which is why “we must work together—families, children, clinicians, care teams—to maximize skills and independence while providing the support needed to self-manage effectively. We must meet families where they are to support and enhance their unique capacities.”

Only with the passage of the Affordable Care Act in 2010 did the family once again become insurable, which “dramatically widened” Matthew’s options for his adult life. Yet health policy still does not work for many families, Rodgers said. The legacy of medical debt continues to touch every aspect of her family, and they still face substantial out-of-pocket costs. “The truth is that quality care costs, but the investment is worth it. Keeping children and families at the heart of health care financing decisions at all levels is the only way to have an American health care system that works. We must raise our collective voices, and votes, to advocate for a system that works for families.

“For Matthew, his sister, our family, and every family raising a child with complex health care needs, policy matters,” Rodgers said. “It touches our lives every day.”

## **Organization of the Symposium**

Rodgers’ comments led off a symposium entitled, “Designing Systems That Work for Children With Complex Health Care Needs,” sponsored by the Lucile Packard Foundation for Children’s Health in Washington, DC, on December 7-8, 2015. The foundation, which was founded in 1997, has the mission of elevating the priority of children’s health and increasing the quality and accessibility of children’s health care through leadership and direct investment. Grantmaking that focuses on improving systems of care for children, especially children with chronic and complex health conditions, began in earnest in 2012.

Children with complex health care needs are a sentinel population for shortcomings in the organization and financing of children’s health care in the United States. They confront and thereby highlight issues that affect pediatric care and the transition to adult care for all families. At the same time, they have particular needs that often are not met, such as structuring and coordinating care and services from many different providers.

The symposium provided a forum for learning from those working on issues within the general child health care system that have particular relevance for the care of children with complex health problems. Ongoing changes in the health care system create both problems and opportunities for children with medical complexity. Symposium participants discussed these problems, identified possible solutions, and described ways in which current and future opportunities could be grasped.

The symposium was organized around six topics:

- National health care policy and children with health complexity (Chapter 2)
- Risk assessment and tiered care (Chapter 3)
- Care planning and coordination (Chapter 4)
- Supporting self-management (Chapter 5)
- Models of co-management and team care (Chapter 6)
- Cost, financing, and payment for complex care (Chapter 7)

Each of the six sessions featured a major presentation followed by comments from two respondents and a moderated discussion. This summary of the symposium should not be seen as the conclusions of the symposium participants as a whole. Rather, it seeks to lay out many of the issues associated with children who have complex medical needs as a guide to further discussion, research, and action.

## Themes of the Symposium

Several important themes emerged from each of the panels that served to structure the discussions:

**National health care policy:** The United States has made tremendous progress in providing insurance coverage for children, with fewer than 5 percent of children ages 0 to 18 uninsured in 2015, but children with special health care needs still face barriers to adequate care and have unmet needs. Model programs underway around the country are providing these children with the care they need, including care coordination services and integrated care management. But many aspects of health care reform, including alternative payment models, are not designed with children in mind. In addition, behavioral health needs are omnipresent, under-recognized, and under-funded.

**Risk assessment and tiered care:** The term *complexity* is generally used to characterize something with many parts that interact with each other in multiple ways, creating feedback loops that result in nonlinear behaviors that can be hard to understand and change. In medicine, complex problems involve patients, clinicians, care teams, and support systems, among other factors. In addition, social factors can have direct and indirect impacts on health outcomes, adding dimensions of social complexity to medical complexity. One way to think about complexity is to consider it as part of a system of risk stratification, which in turn can shape the delivery of care and other services.

**Care planning and coordination:** Children with medical complexity typically have a variety of needs, which requires that they receive care from different sources. The goal of care planning and coordination is to address the interrelated medical, social, developmental, behavioral, educational, and financial needs of children and families to achieve optimal health and wellness outcomes. Yet care planning and coordination often remain fragmented and incomplete because of financial and organizational constraints. Care coordination that integrates patients and families into the process can increase their activation in care. In particular, a family-centered approach can be responsive to family challenges, priorities, and strengths while improving and streamlining care delivery.

**Supporting self-management:** Many children with complex health care needs have the agency and autonomy to self-manage or direct their own care. This self-management typically undergoes a trajectory, from the child or adolescent depending fully on the parent or caregiver, to a situation of increasing autonomy, to in some cases independence with a limited role for a parent or caregiver. Both children and their families need opportunities to succeed and opportunities to fail, which makes the establishment of self-management much like parenting in general. It also requires that children and their families have access to information about their own care.

**Models of co-management and team care:** Caring for a child with complex health care needs typically requires a variety of medical and community services. Co-management and team care are needed to coordinate and optimize these services, especially given that these services typically are not accustomed to working together. Generating a culture of collaborative care can increase communication, build relationships, and access resources. In addition, making the business case for co-management can gain funding and support for a comprehensive approach.

**Cost, financing, and payment for complex care:** Increased expenditures on Medicaid are causing many states to pursue health care reforms, including accountable care organizations, pay-for-performance plans, and bundled payments. Important elements of these new approaches are flexibility, the integration of behavioral and physical health, coordination with home- and community-based services, financial viability, and stakeholder involvement. If structured to meet the needs of children with medical and social complexity, such changes can be transformational.



## Session 1: Children with Health Complexity and National Health Policy

The policies that shape and govern care systems for children with complex health care needs have a dramatic impact on their lives. As such, the first session of the symposium looked at these policies and their implications at the national, state, and local levels. As the presenters observed, these policies have undergone substantial changes in recent years, yet they still leave major gaps in the services that are available to children with health complexity and their families.

### Evolving Policies and Unmet Needs

The United States has made “enormous strides” in providing insurance coverage for children, noted Cindy Mann, partner at Manatt, Phelps & Phillips, LLP in Washington, DC. Largely because of the expansion of Medicaid and its companion Children’s Health Insurance Program (CHIP), only about 5 percent of U.S. children ages 0 through 18 were uninsured in 2015 (Figure 2-1). Five percent uninsured is still “too much,” said Mann. “We need to get to 100 percent. But it’s a major step.”



Figure 2-1. The uninsurance rate of children ages 0 to 18 has dropped to below 5 percent. Source: 2013, 2014, and 2015 National Health Interview Surveys

As a result of the Affordable Care Act, the Medicaid program now anchors a new coverage continuum that provides a mechanism for insuring people who do not have affordable health care coverage. However, a coverage gap exists for low-income adults in states that have chosen not to expand Medicaid under the act. At the time of the workshop, 30 states plus the District of Columbia had expanded Medicaid, and “hopefully we will continue to see more states join,” said Mann. If low-income parents are struggling with a lack of health insurance coverage, their own

health can be affected, which can adversely affect the health of their children. “We can't forget that gap in terms of our focus on children with complex medical needs,” Mann observed.

Enrollment and retention procedures also have changed dramatically for Medicaid and CHIP. States have a variety of options to simplify enrollment and renewal and promote continuity of care for children. Examples include enlisting managed care organizations to assist with renewals, using data from food assistance and other sources to automatically enroll in Medicaid/CHIP, and making broad use of population-based presumptive eligibility. However, not all of these systems work as well as they should, said Mann. States need to “take the burden off the families, which is particularly important for kids and families with complex health care needs.” For example, states do not need to do annual re-determinations if a child’s situation is stable, she recommended. “We're not done with the revolution that has happened in terms of enrollment and retention. There's yet more to be done.”

Mann used the definition of children with special health care needs as “those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition that requires health and related services of a type or amount beyond that required by children generally.” According to a report from the Lucile Packard Foundation for Children’s Health (2014), 20 percent of children in the United States, and 23 percent of children with public insurance, have special health care needs; 60 percent of children with special health needs have “more complex needs”; and 17 percent of children with special health needs have four or more chronic conditions. Mann noted in addition that children with medical complexity account for 34 percent of Medicaid spending on children. At the same time, nearly half of Medicaid spending for children with medical complexity is tied to hospital care, while only 2 percent goes to primary care. “How do we switch that balance?” she asked. “How can we persuade policymakers and budgeters that in doing so, it is not only good for families, good for children, and good for society, but good for the bottom line in terms of shifting a focus to getting kids out of hospitals as much as possible.”

Even though children with high medical costs show up prominently in statistics, “they’re getting lost, in some respects, with the focus of health care costs and what we can do to bring down health care costs,” said Mann. In general, adults with special health care needs are spotted more easily in Medicaid than children.

Children generally have good access to services in the Medicaid program, Mann observed. However, some children with special health care needs face barriers and have unmet needs. About 35 percent of families that had a child with special health needs had trouble accessing community-based services, and 22 percent of families had problems getting referrals to specialists (Lucile Packard Foundation, 2014). Approximately 19 percent of families with a child with special health needs reported at least one unmet need (such as preventive care, specialist care, or prescription medicine), and this number increased to 44 percent when the child was medically complex. Medicaid families reported 32 percent more unmet needs compared to families with private insurance, and uninsured families reported four times the number of unmet needs. Children in systems such as foster care or the juvenile justice system tend to have even greater unmet needs, said Mann. For example, many of the 400,000 children in foster care

nationally have significant health care needs, including behavioral health, mental health, and physical health issues. Sixty percent have a chronic medical condition, and a quarter have more than three. Between 50 and 80 percent have moderate to severe mental health issues. Similarly, of the more than 70,000 justice-involved children, over two-thirds reported a health care need, and 50 to 75 percent have a mental health or substance use disorder (Acoca et al., 2014).

Why do so many children have so many unmet needs, Mann asked. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit provides comprehensive coverage for children under 21 in Medicaid. It covers “necessary health care, diagnostic services, treatment, and other measures... to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services.” It promotes the early identification and treatment of health issues in children, including mental health and substance use disorders. It provides all treatment services that children need and that Medicaid can cover, even if Medicaid does not cover the service for adults. As Mann said, “the law in the Medicaid program, with respect to basic physical and mental health care needs, could not be more strong.”

The disconnect between the law and the unmet needs of children with medical complexity arises from several factors, according to Mann. Many practitioners do not know what EPSDT requires. Also, children with complex health care needs often require services that go beyond what would be covered by the Medicaid program, so not all of the needed services can be accessed through EPSDT. Special waivers are available to get some of these services, but the waiting lists can be long. Finally, said Mann, “systems of care are not necessarily designed in such a way to assure that all health care needs for kids with complex medical needs are met.”

She concluded her presentation by listing several efforts underway around the country to provide children with the services, including care coordination services and integrated care management, needed by children with medical complexity.

- The University of Illinois Coordination of Health Care for Complex Kids program is building a “medical neighborhood” to bring care to patients where they live, work, and attend school and establishing care management teams with embedded navigators.
- The Massachusetts Alliance for Complex Care is developing comprehensive care plans for children and families through comprehensive assessment, assigning families a family navigator, and providing behavioral health services.
- The Coordinating All Resources Effectively program for children with medical complexity is improving care for medically fragile and intense needs children by creating a tiered system of care, designing new payment systems and models, and creating a learning system for providers and payers.
- The Special Needs Program (SNP) for children with medical complexity in Wisconsin is enhancing and expanding the SNP currently in place at Children’s Hospital of Wisconsin, establishing multidisciplinary care teams, and expanding SNP to an ambulatory setting.
- New York State is building a Medicaid health home program to serve the unique needs of children who have complex physical and/or behavioral health conditions, with 174,000 children statewide who may be eligible for health home enrollment, including many children in foster care.

- The Children’s Hospital of Philadelphia is piloting the Compass Care program to improve care management and coordination of children with the most complex health needs, developing a comprehensive care plan for each child with his or her unique needs in mind, and facilitating communication between doctors, payers, and families to clearly define roles and ensure that appropriate decision-makers are at the table.

In mentioning these programs, Mann specifically called attention to the issue of behavioral health integration. “It is sadly not the reality in so many of our communities, for kids or adults,” she said, though greater attention has been given to the issue in recent years.

The bottom line, said Mann, is that children “are not getting the focused attention that other people with complex medical needs are getting in our system.” But these children are a critical part of the high-needs population and need to be a focus of delivery system reform, she said. “We need to make sure that our policymakers, at both the state and the federal level, understand who these kids are and what systems needs they have.”

## **The View from the States**

David Keller, vice chair of clinical affairs and transformation in the Department of Pediatrics at the University of Colorado School of Medicine, discussed several of the issues raised by Mann from the perspective of his experiences in the states of Massachusetts, Rhode Island, and Colorado. First, he agreed that children with complex health care needs are not the priority in the current discussion of Medicaid. “Right now, Medicaid policy is not focused on kids; it's focused on adults.” The expansion of Medicaid is new and is consuming most of policymakers’ attention, and “that probably is going to be true for the foreseeable future, because this new expansion is a big deal.”

Another reason why children with complex medical needs can be overlooked is because alternative payment models are not designed with children in mind, Keller said. In children’s health practice and policy, primary prevention is more important than chronic disease management, rare diseases account for a greater share of spending than with adults, the focus is on long-term rather than short-term outcomes, and demonstrating shared savings may not be possible. One consequence is that children and adolescents ages 0 through 18 consume only about \$359 billion of the total expenditures on health care in the United States of \$2.7 trillion, despite making up a quarter of the population. “That’s the challenge that we’re working against.”

A related issue is that current measures of quality and performance in health do not reflect the needs of children. Keller argued that these measures need to reflect five D’s:

- Developmental change—looking at life course outcomes with multiple inputs.
- Dependency—including families.
- Differential epidemiology—focusing on behavioral health, mental health, and education.
- Demographic patterns—accounting for diversity and poverty.
- Dollars—providing incentives with more than shared savings.

Finally, he noted that behavioral health needs are omnipresent, under-recognized, and under-funded. Mental disorders are the most costly condition in children (Figure 2-2), but payment systems are not designed to integrate care for these disorders into child health care. “Trying to move back into integrated care is critical to the work, but there are huge barriers at both the federal level and at each of the state levels to going forward.” The difficulty is compounded by the fact that the United States has 56 different state- or territory-based health service ecosystems, with variation in managed care penetration, the relationship between CHIP and Medicaid, essential health benefits in marketplaces, and the relationship between Title V of the Maternal and Child Health Services block grant and the Vaccines for Children programs within each state. When Keller was practicing in Massachusetts, he had patients from Rhode Island and Connecticut as well, and each state’s Medicaid agency had a different set of rules and different sets of coverage.

Keller also observed that a great deal of “churn” is currently going on within the health care systems of each state and territory. Hospital consolidation, practice consolidation, and the establishment of clinical integrated networks are all taking place. Academic health centers and federally qualified health centers are trying to figure out where they fit into the current health care scene, and health plans are developing multiple sets of poorly aligned metrics for payment that stress practices’ analytic capacity. “If you have to come up with three different measures of what your immunization rate is because it’s defined differently by three different health plans, that’s a huge workload for a practice.”

Providers need to be at the table to ensure that the needs of children are not forgotten, Keller concluded. They need to learn to measure processes and outcomes, develop a quality improvement and analytic infrastructure, build the capacity to coordinate care, and shore up partnerships with behavioral health and other providers in their organizations. “We need to not forget what we’re about, which is taking care of the kids.”

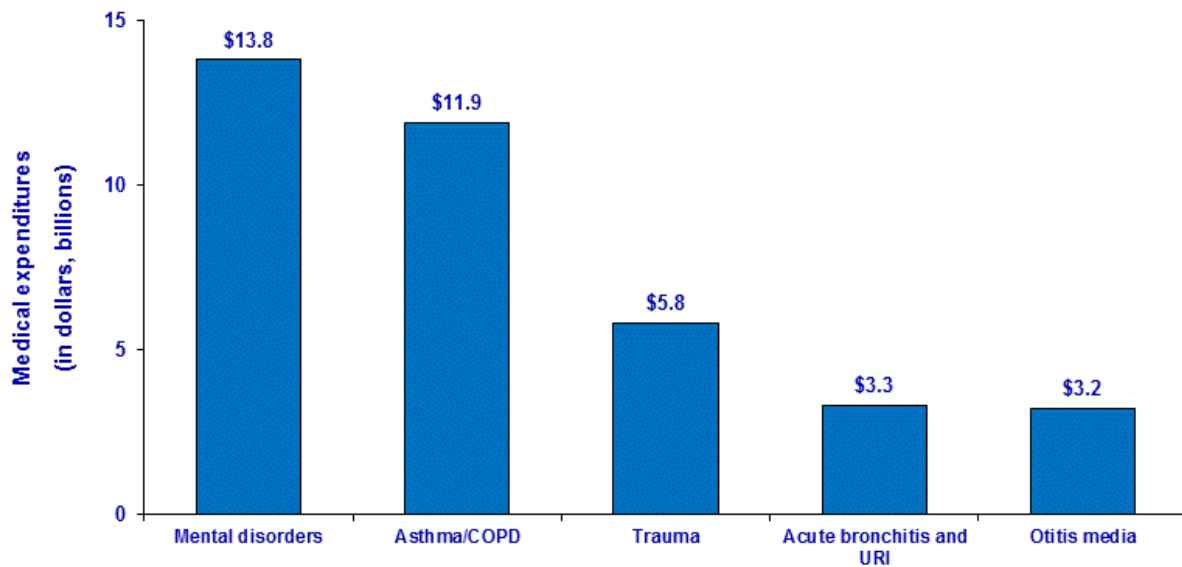


Figure 2-2. Mental conditions are the most costly condition in children. Source: Center for Financing, Access, and Cost Trends, AHRQ

## State Initiatives That Promote the Triple Aim

Like Mann and Keller, Carolyn Langer, chief medical officer of MassHealth (and the mother of a 19-year-old with autism and intellectual and developmental disability), touched on the challenges posed by the status quo, including the emphasis on acute and episodic encounters, fragmented care, poor care coordination, a lack of focus on population health, poor management of chronic diseases, payment for the volume of services rather than their value, lack of access, inadequate data, poor transparency, the slow dissemination of evidence-based practices, poor integration with behavioral health or long-term services and supports, and concerns over workforce capacity and development. But she focused mostly on the potential for payment reforms that could share savings, improve outcomes, and lower costs. These payment reforms lie upon two continua ranging from fee-for-service to global-payment systems and from limited integration to full care integration (Figure 2-3). “The message I would like to convey is how you latch onto these models,” she said. “How do you ensure that they're designed with the pediatric voice in mind—in particular, the voice of the child with complex health care needs?”

Massachusetts was one of the states funded to do demonstration projects under the 2009 Children's Health Insurance Program Reauthorization Act (CHIPRA), and it used its grant to develop an organization called the Children's Health Quality Coalition. It is a multi-stakeholder coalition of individuals across all segments of Massachusetts, including payers, providers, families, academicians, and policymakers. “This group has been extremely active and vocal as we have rolled out some of our alternative payment models,” said Langer. Their input shaped the MassHealth Primary Care Payment Reform, which is a new payment and care delivery model

that supports the attainment of the triple aim. Langer used the reform as an example of an alternative payment model that tries to address the needs of children with complex health care needs.

The initiative seeks better experiences through a patient-centered medical home model of care and integrated behavioral health; better care through bundled payments and payment for quality to coordinate care and improve performance; and reduced health care costs through shared savings. Bundled payments for all the services that fall into a primary care practice have been combined with medical home activity payments to enable pediatricians to build an infrastructure for services not reimbursed in the past. In addition, quality incentive payments provide an annual incentive for improving primary care performance, and primary care providers share in savings on non-primary care spending, including hospital and specialist services.

Practices are required to opt for one of three different behavioral health integration tiers. Under tier one, they are required to have a written agreement with a behavioral health provider to coordinate care and integrate medical and behavioral health care. Tier two has a requirement for co-location of a master's or doctoral level behavioral health provider for no less than 40 hours per week. Practices have to be able to schedule a behavioral health service appointment within 14 days from the time of request, and this tier has a requirement to engage in more active screening and assessments. Tier three requires a co-located psychiatrist for at least eight hours a week and 24/7 access to a behavioral health provider. She also cited, in response to a question, the Massachusetts Child Psychiatry Access Program, which is a telephonic resource that provides pediatricians with the tools and knowledge they need to treat children with behavioral health issues. "We have gotten phenomenal feedback on this program," she said.

The Comprehensive Primary Care Payment (CPCP) initiative does not limit practices to revenue streams that are dependent on the volume of appointments. Rather, it provides incentives to practices to invest in infrastructure and gives practices the flexibility to provide care as their patients need it, without depending on fee-for-service billing codes. The initiative may support an expanded care team, community health workers, peer supports, phone and email consultations, group appointments, targeting appointment length to patient complexity, or other services. It allows a range of primary care practice types and sizes to participate; it provides financial support for behavioral health integration by including some outpatient behavioral health services in the CPCP; and it ensures support and access for high-risk members through risk adjustment based on age, sex, diagnosis, social status, or comorbid conditions.

While the CPCP does prescribe certain elements such as the requirement that every practice have a care coordinator, it does not take a one-size-fits-all approach, said Langer. Some practices are urban, some are rural. Children with special health care needs are a heterogeneous group, so practices need flexibility to best serve the populations that they are treating. Some practices have hired peer supports or parent supports. Others have invested in community health workers. Some are experimenting with telemedicine and telehealth. "The bottom line," said Langer, is that "the primary care providers are at the point of care. They know their populations best. We wanted to make sure that we could afford them as much flexibility as possible to reach their patients where

they work, live, and play.” At the same time, a risk-adjustment system reassures practices that they will be adequately compensated for managing this pool of patients.

This new model has several key points of emphasis, Langer noted:

- Patient-centered care
- Multidisciplinary teams
- Enhanced access to care
- Self-management support
- Planned visits and follow-up care
- Population-based tracking and analysis
- Inclusion of quality improvement strategies and techniques
- Clinic system integration
- Care management
- Care coordination

In response to a question, Langer pointed out that the program is still in its early phases, so it is too early to see improvements in quality and lower costs.

She also pointed to several key implications of alternative payment models for the care of children with special health care needs. By expanding the medical home model, these models promote care coordination and care management, provide incentives for coordinating care with other providers and community-based organizations, and offer flexibility to meet the needs of special populations. These models can ensure the adoption of medical home elements through certification requirements, contractual obligations, and quality measures. Processes that improve pediatric care may also improve adult care (and vice versa), and stakeholder input is valued and can be impactful. Finally, learning collaboratives can bring people together and share lessons learned.



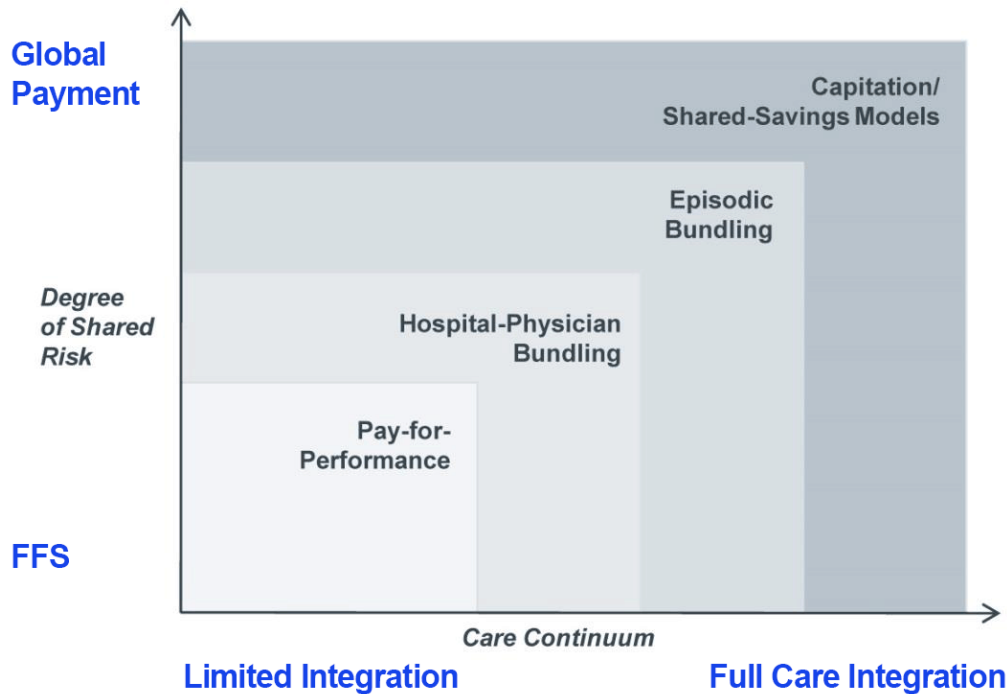


Figure 2-3. Payment reforms provide opportunities for shared savings while shifting risks to health systems.

## Toward a More Integrated and Comprehensive System

How to move toward a more integrated and comprehensive health care system that reflects the social determinants of health was the major topic of the discussion session. As David Labby of Health Share of Oregon noted, many adults with major health care needs started off as children with troubled lives, often because their parents had troubled lives. As a result, addressing family problems during childhood could save decades of more intensive care. For example, he suggested that kindergarten readiness might be a metric that pediatricians and other health care providers could adopt.

Keller pointed out that the expansion of the Medicaid program offers the opportunity to deal with these issues. He observed that “Medicaid is the only insurance in the country that is held to the standards of EPSDT.” Health care providers need to use the T—treatment—in EPSDT as “a sword and shield as you go forth.” Though, as another symposium participant pointed out, the T is not always observed, the standard is stronger even than private insurance in mandating that treatment be provided to children and their families.

One problem in applying this standard, said Mann, is that “budgeters have a much smaller window than the lifetime of a child in terms of trying to find those savings.” To the extent that coverage can be continuous and aligned over the life course, she said, a long-term perspective on health will be easier to implement.

However, many of the services families need are not necessarily covered by the health care system, she added. Health care systems are starting to work more closely with community-based organizations. They can forge linkages with the resources and social agencies that are available. However, gaps in financing often limit what can be done. For example, housing is important for a family's well-being, but the resources needed for affordable housing may not be available. "The stress brought from eviction is not necessarily something, even if we have our antenna up, that we can always avoid."

Jeffrey Goldhagen of the University of Florida College of Medicine in Jacksonville and Eileen Forlenza of the Colorado Department of Public Health and Environment both raised the issue of child care centers, schools, and other educational settings as an underutilized resource to improve the health of children. As Goldhagen put it, "Children spend a small amount of time in hospitals, an even smaller amount of time in out-patient centers, but an enormous amount of time in schools, communities, their homes, and so forth."

Keller pointed to the work on inclusion that has been done in schools. Serving children with special health needs in schools requires coordination, integration, and common metrics, he observed, though these metrics may not extend as far as high school graduation or college readiness. However, kindergarten readiness is a valuable measure that has been implemented in some places. On this topic, Mann pointed to the need to continue working on the policy issues that have constrained flows of information between the educational and health care systems. Similarly, policy issues are at the center of funding flows between health care and education, such as whether the provision of health care services in schools can be billed to Medicaid.

Forlenza also raised the issue of care coordination done by families as a reimbursable expense. Mann pointed out that family caregivers can be reimbursed by Medicaid for home- and community-based services, though it is a state decision and is not driven by federal regulations. Less progress has occurred on paying for family care coordination, though "we have such a workforce shortage that it makes a lot of sense.... There's nothing in federal law that will prohibit it. It's really about licensing, certification, and the rules that a state comes up with." Langer added that the expertise of parents is "a really important resource for families to have, so you may want to think about how new alternative payment models could leverage parent resources."

California State Senator Richard Pan emphasized the importance of continuous care coordination, so that new care coordinators do not have to continually learn about the children they are serving. "That relationship has value, and we should find a way to pay for it." As Keller responded, enhancing continuity will require building the value of the relationship into payment systems and upgrading the training and retention of care coordinators. Research on the value of this relationship could help make a case for change.

## Session 2: Risk Assessment and Tiered Care

Addressing the needs of children with medical complexity requires understanding what medical complexity is. Three speakers at the symposium addressed this issue from different perspectives. The main speaker considered the attributes of medical complexity and the implications of these attributes for problem-solving. The two respondents discussed a tiering system for children's health care and the role of social complexity in risk assessment and tiered care.

### A Scientific Approach to Medical Complexity

Even when he was a resident at the University of Washington, Chris Feudtner, who is now director of the Department of Medical Ethics at Children's Hospital of Philadelphia, was interested in medical complexity. Among his patients were a 17-year-old boy, a refugee from Serbia, who was curled up in a ball because of his osteogenesis imperfecta, when Feudtner first saw him; a young girl who had terrible complications from a bone marrow transplant; and an adolescent with chronic renal insufficiency who had behavior problems that caused him to pick at his dialysis port until he almost bled to death. All physicians might agree that these patients have complex needs, but what makes their conditions complex, Feudtner asked. "We might all agree for different reasons."

Feudtner said that he has become convinced that optimizing outcomes for children with complex health needs and their families requires developing a rigorous scientific approach to understanding and managing medical complexity, which in turn requires a theory of medical complexity. A theory would clarify terms and concepts, promote development of a common language, provide something to argue against, and suggest useful areas to investigate or develop. Toward that end, Feudtner laid out at the symposium some "ideas that need to be tested."

First, classification methods are tools for a job, he observed, not ends in themselves (Berry et al., 2015). They might be based on diagnoses (or procedure codes), function, or other attributes, but no classification works for everything. "We know this. Let's acknowledge it and figure out ways to make these tools work better."

Risk stratification is a specific type of classification that classifies children into bins of increasing levels of risk. The question is "risk of what," noted Feudtner. The risk could include mortality (during what time frame?), readmission (when? what type?), preventable morbidity (what kind?), unmet needs (what needs count?), cost (to whom?), or many other negative outcomes. In addition, risk stratification often amounts to cause stratification, Feudtner observed, which is not the same as assessing unmet medical needs. "They may be collinear, [but] it's not complete." As a result, risk stratification has at least the potential to be obfuscating or disingenuous.

Risk stratification takes the form of a quantitative prediction, he observed: "Based on what we know about you now, you are at  $x$  percent risk of  $y$  at time  $z$  in the future." But other foci of interest may exist. One possibility is to identify patients or clinical programs that have opportunities for improvement. For example, an "improvability index" might be tied to a

measure that would identify groups of patients managed by a particular clinical care team whose outcomes are consistently worse than similar groups of patients managed by other teams. In such a case, a team in a particular location might need to undergo a “teamwork boot camp,” said Feudtner.

Feudtner explained that there is no one definition of complexity. But the term is generally used to characterize something with many parts that interact with each other in multiple ways. As a result of the feedback loops established by these connections, relationships between parts of a complex system tend to be nonlinear, yielding the potential for either synergistic success or cascading failure.

All human beings are complex systems, so no one individual can be more complex than another. However, individuals can have complex problems. These complex problems do not entirely emanate from or reside in patients, Feudtner observed. Rather, they are the product of patients, clinicians, care teams, and support systems, among other factors.

Complex problems can be distinguished from complicated problems, in which the components do not interact. “If it’s simply complicated, you can do what a resident is taught to do: divide and conquer.” By taking care of problems one by one, a clinician can eventually solve them all. But complex problems “don’t work that way,” said Feudtner. They require a more complicated skill set, because the divide-and-conquer approach may not be the most efficient algorithm. Because of the interactions among the components, addressing one problem can generate other problems. Drugs may have side-effects or interact with each other, and technologies can both alter and create problems, with complexity increasing according to a power law of the interacting components. “This non-independence of the problems is part of what we are asking physicians to tackle,” said Feudtner, but physicians are not taught how to do it.

In addition, with complex conditions, black swan events can occur, so that a single outlier in a population can disrupt an entire system. “For six years leading up to that [event], it’s going to look like you’re getting paid way too much, and then one year you’re going to take a bath because of a huge outlier. The law of huge numbers does not work to protect you against that.”

Problem-solving can be difficult with complex systems because of ignorance about components or interactions. “What we don’t know may in fact be the key missing part,” said Feudtner. In fact, a useful approach can be to hypothesize the existence of an unknown component that would explain a set of problems. For example, parents may have a mental health issue that they have not disclosed, or a transportation problem may interfere with care.

Uncertainty about the components of a problem makes finding a solution less certain or assured. This uncertainty—which is always present, acknowledged or not—is handled differently by different people and can create conflict or decisional paralysis. In this case, making the management of uncertainty an explicit part of group problem-solving can be helpful, Feudtner said.

An even greater difficulty is a lack of clarity or agreement about what problem to solve. Trying to solve a problem shrouded in the mist of disagreement or poor communication is foolish, he said.

By the same token, solutions need to be defined. What does success look like for a given well-defined problem? “We often have multiple objectives that we don't share with each other. Our vision of success differs.” The solutions then become part of the complex system, in which case maintaining all the solutions can itself become a complex problem.

People are often reluctant to wind down established solutions, even if they are only partial solutions. The question then becomes how to simplify care. As Feudtner put it, “We need to have very systematic ways of trying to simplify care back to the minimum that keeps the child stable, because the solutions are often part of the problem.”

Another source of difficulties is having too many cooks in the kitchen. The communication load increases by the square of the number of people communicating. People can have differing goals or values, which result in different solutions that have to be traded off against one another. Reducing the number of clinicians can be helpful. “Sometimes the best thing you can say is, ‘Who needs to be on the core team here. Everybody else is not invited to the meeting.’” But the optimal number of clinicians and optimal amount of time to spend on a patient is often not clear, Feudtner added.

Medical problems have additional aspects of complexity. What is complex for one clinician might be clear for another. A subspecialist may know exactly how to fix a problem, but more often, interdisciplinary teams are needed. However, the education of practitioners to work in interdisciplinary settings and the management of interdisciplinary teams are both relatively undeveloped topics.

Complex medical problems are often hierarchically related, where one thing drives or depends on other things and some problems are nested within other things. For example, a problem can depend on the performance of a service team or social circumstances—as when a parent is unable to adhere to a follow-up plan because of the lack of a car. “If you don't fix that, you're not going to be able to win this battle.”

Complex medical problems require that families and care teams confront adversity and be able to cope, adapt, problem-solve, and execute, said Feudtner. Given that resilience and abilities in all these skills are key influencers on outcomes, the question becomes what interventions can increase these abilities and resilience.

Care coordination can speed up planning, enhance execution, and lower the total effort for a solution. But this is not all that complex medical problem-solving requires, according to Feudtner. Organizing problems into hierarchical structures where “this drives that” can help identify high leverage points. For example, it may be possible to seek positive cascades, where altering one problem makes many other problems easier to solve. “There should be a theory of what care coordination can do,” Feudtner said. “I see a lot of people writing up elaborate care plans, and I'm not sure that anybody other than the person writing it is reading it, and that worries me.”

Reducing complexity can make problems more tractable. Feudtner advocated practicing “the art of thoughtful omission,” though not beyond a point of diminished effectiveness. Focusing on a

smaller number of high-leverage problems can help everyone stay focused on the things that need to be done to solve those problems. “You have to pick a few things and really get them done right.”

*N* of 1 trials may be necessary, he said, and researchers need to figure out how to conduct such trials effectively and efficiently. Is something helping a child? How often should attempts be made to wean a child off a medicine to be sure that it is necessary?

Medical care for complex patients most often involves a group of clinicians working together in an ad hoc manner, and the performance of this individualized ensemble is part of the complexity of the problem-solving. Training for this kind of work is needed, said Feudtner, “but, again, it’s not something that we’re taught. As a physician, I was never taught how to potentially lead an ad hoc team.” Because problems are almost always related, honest conversations are needed about how to use these relationships to do problem-solving.

When he gets involved in the care of medically complex patients, Feudtner often encounters leadership vacuums, he said, and this problem could get worse given ongoing changes in health care and medical training. “We need to figure out how to help strengthen leadership. It doesn’t need to be the physicians, but somebody needs to be leading the team... spelling out what the problem is, clarifying the goals, confronting the tradeoffs.” Otherwise, people are left chronically unsure of what they should be doing and what their expectations should be.

Finally, he pointed out that planning is worthless unless plans can be executed. “I often say that decision-making is vastly overrated in health care. You have to not just make the decision but execute and sustain the plan.” Teamwork, communication, and other steps to a solution all need to be studied and developed, Feudtner said. “We have to become much more hard-nosed about why we think these things might work to improve outcomes.”

Finally, Feudtner left the symposium participants with some additional questions that bear on complex medical problem-solving:

- Can differences in cognitive styles of complex problem-solving be accommodated with individualized decision support?
- Are some clinicians better at complex problem-solving than others?
- Can clinicians be trained to be better complex problem-solvers?

In ten years, said Feudtner, he would like to see “a whole field of complexity management that has much more rigorous science behind it than what we have today.”

## **Tiered Pediatric Care at Denver Health**

A specific way to think about complexity is to consider it as part of a system of risk stratification. Simon Hambidge, director of ambulatory care services at Denver Health and professor of pediatrics and epidemiology at the University of Colorado School of Medicine, described one such system at Denver Health, which is a large integrated safety net health care

system. The system includes eight federally qualified health centers (FQHCs), a large level-one trauma center, 17 school-based health centers, and the Denver public health department.

In particular, Hambidge focused on community health services, which he oversees. In 2014, Denver Health's community health services had 433,000 visits, with 140,000 unique patients, including more than 65,000 children and adolescents. Almost all were below 200 percent of the federal poverty level, representing over half of the Medicaid patients in Denver. One in 15 Americans receives health care through an FQHC, with a higher rate for children and an even higher rate for poor children. "If we're going to talk as a country about taking care of these kids, it's imperative to engage our FQHC colleagues."

Denver Health has pediatric and family medicine clinics, in addition to taking care of 12,000 children in its school-based health centers. It works with the city and county to do evaluations for children suspected to be victims of abuse and neglect, with close connections to a foster care clinic. Most of the children in the foster care system are seen through Denver Health, which creates a health passport that follows them wherever they go.

An important goal for risk stratification, said Hambidge, is to define the relevant population. If set up right, risk stratification can help identify children who have fallen through the cracks. Denver Health began by using a risk stratification tool that had been used by the state Medicaid office. But this tool was not working well for children, so the system instead turned to a set of clinical risk groups (CRGs) that includes nine risk levels. However, with nine risk strata based on different codes and utilization, the tool was not clinically actionable. Instead, every CRG was assigned to one of four "tiers" by two pediatricians and one data analyst. Additional criteria are then used to override the CRG-assigned tier for some children.

Tier one is basically healthy children, and tier two includes children with one or two chronic but stable conditions. A child with certain mental health diagnoses is classified as tier 2 or tier 3 and receives a specified level of care coordination services. Other children in tier 3 include those with complex seizure disorders or requiring intensive rehabilitation services. A registry for children with special needs, set up in 2008, identified many of the system's medically complex children, based both on ICD9 codes and pharmaceutical usage, and all of these children are in tier four. A history of premature birth with a mother targeted for future interventions and high hospital or emergency department use also affects the categorizations. After the assignments were made, tier one had about 50,000 children and tier four about 500 children.

The categorization in turn shapes the delivery of enhanced care (Johnson et al., 2015). With each higher tier, children receive more services (Figure 3-1). For example, tier one children receive text reminders for well child visits, immunizations, and flu vaccines. Tier two children receive case management for chronic diseases from patient navigators trained to deal with specific diseases, such as asthma. Tier three children receive complex case management from nurse care coordinators and other professionals, such as navigators linked to the Denver Housing Authority. Tier four children receive care in high-intensity treatment clinics. Costs vary greatly among tiers. Tier one children cost about \$76 per member per month, while tier four children cost around \$4,500.

Care teams were redesigned to reflect the new system. The system added patient navigators, behavioral health clinicians, nurse care coordinators, and high-intensity treatment teams. The goal, according to Hambidge, was to transform practice by integrating new staff with existing staff to provide team-based care.

The new system has produced improvements in well child visits, immunization rates, asthma compliance, and other measures, reported Hambidge. It also has been very well received by staff and families. It is expensive, because of information technology and personnel expenses. But initial results demonstrate that the new approach has saved the system \$7 million, largely because of reductions in adult use of tier four care. Tier four pediatric populations also saw a reduction in utilization.

The changes are ongoing, Hambidge said. Considerable progress has been made at the tier one and four levels, but at levels two and three, “we still have a lot of work to do.” For example, one goal for the future is to integrate behavioral health and the social determinants of health into the tiering model, especially since “a lot of medical utilization and cost is driven by behavioral health.” Once the tiers are set up, Hambidge noted, they can be populated with measures of social complexity as well as medical complexity.

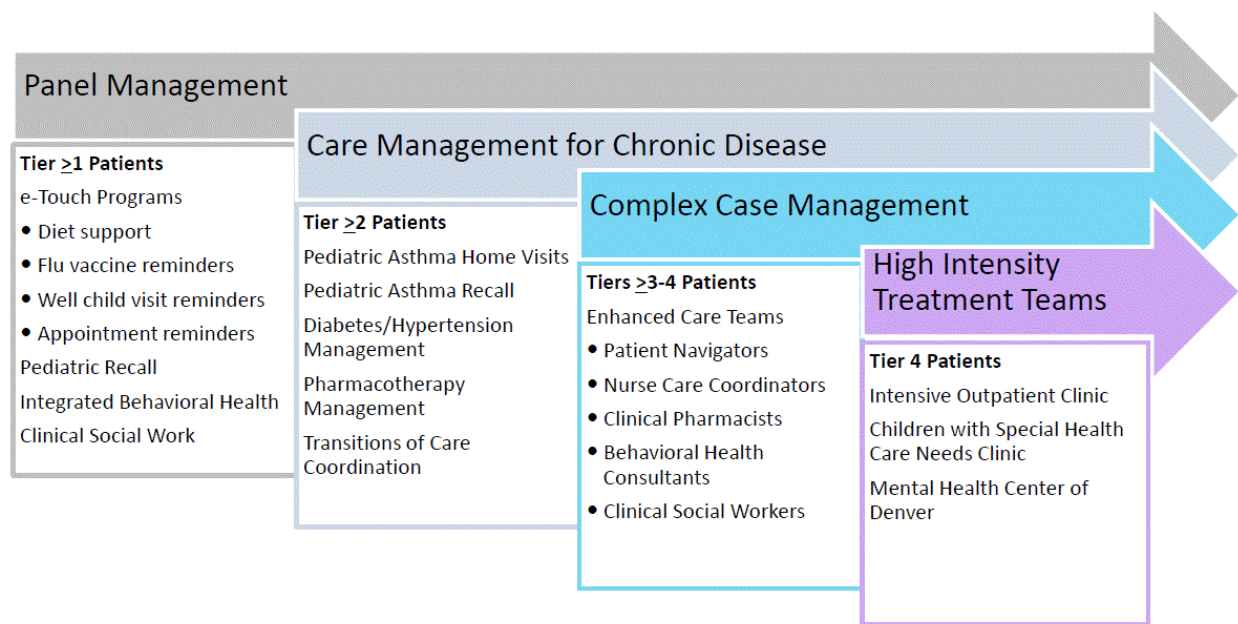


Figure 3-1. Children in higher tiers receive additional layers of treatment intensity. Source: Denver Health.

### Adding Social Complexity to Tiered Care

U.S. health care is being asked to increase the quality of care while reducing costs to produce high-value care. But “what if high quality actually costs more?” asked Rita Mangione-Smith, professor and chief of the Division of General Pediatrics and Hospital Medicine at the University



of Washington. “It's expensive to give high-quality care,” she continued. Perhaps if such care were limited to children with the greatest needs it would not impose an undue burden on health care systems, but “if you want to be more inclusive and get down into tier three, it's going to start getting prohibitively expensive.”

The question then becomes how to allocate limited resources to children with complex needs. Mangione-Smith focused specifically on social complexity as a factor in this question, which she defined as “a set of co-occurring individual, family, or community characteristics that can have a direct impact on health outcomes or an indirect impact by affecting a child's access to care and/or a family's ability to engage in recommended medical and mental health treatments.” For example, social characteristics like poverty or limited English proficiency are associated with decreased access to and use of primary care, less likelihood of having a patient-centered medical home, and increased hospitalizations for uncontrolled conditions like asthma, Mangione-Smith noted.

Classifications by medical complexity can overlook social risk factors, she pointed out. For example, if a child has a chronic but non-complex condition and a parent has a mental health problem, should that child qualify for care coordination?

Using data from the Washington State Department of Social and Health Services, Mangione-Smith and her colleagues looked at social complexity risk factors in the context of medical needs. For the 2012 population of children enrolled in Washington State Medicaid, about 80 to 85 percent had no chronic conditions. The other 10 to 15 percent had chronic conditions, and children with complex conditions made up about 5 percent of the group.

As a group, these children had much greater exposure to social complexity risk factors than did children not in Medicaid. More than 40 percent had parents with some involvement with the criminal justice system. More than one-third were living in severe poverty or had limited English proficiency. Only about 20 percent of the children had no social risk factors, about 30 percent had one, and the remaining 50 percent had two or more risk factors.

The results of the study were not yet ready for dissemination at the time of the symposium. But Mangione-Smith highlighted the overall result, which is that children with social complexity risk factors are at risk for worse outcomes. “Given limited resources, we need to focus on children with multiple social complexity risk factors, just like we need to focus on children with medical complexity,” she said. “If we have a child with a non-complex medical problem, we need to take into account if that child is also faced with social complexity. We have to do all of the above, and probably more.”

Care coordination can help with access to care and services for children and their caregivers. It also can improve communication between families and providers and among providers. However, it cannot prevent homelessness, poverty, or adverse childhood experiences. “We have to start thinking out of the box and pushing ourselves in how we think about what are the solutions to these problems,” Mangione-Smith concluded. “The medical system can't do it all.”

## The Social Determinants of Health

The final point made by Mangione-Smith was a prominent topic in the discussion session. Daniel Armstrong of the University of Miami Miller School of Medicine pointed to not only the effects of social complexity on health but the effects of health on social indicators, such as the finances of a family. He also raised the issue of prevention, noting that childhood conditions such as obesity have been associated with many later health issues, including cancer. Finally, he asked whether precision medicine can provide “effective treatments in a shorter duration of time, with better adherence than we’ve ever been able to do using our large group strategies.”

Mangione-Smith agreed that “prevention is at the heart of what we do in pediatrics.” But it tends to get left behind, even though it could prevent future costs. Feudtner was somewhat dubious about the potential of precision medicine—“it seems like we keep pushing that forward”—and said that he would welcome an increase in primary prevention. But secondary and tertiary prevention are likely to remain the focus for children with medical complexity, he said, to keep something that is already a problem from expanding.

Read Sulik from the PrairieCare Institute in Minnesota pointed to the difficulties in identifying behavioral health conditions and then gaining access to appropriate, evidence-based, and effective treatments. Yet treating these conditions could greatly reduce costs and the burden of suffering on children, the family, and the community, he said. What is required is reframing how people think about costs.

David Keller of the University of Colorado School of Medicine raised the idea, now being explored in Colorado, of combining the social determinants of health, behavioral health factors, and the medical components of risk toward the goal of maximizing the number of tax-paying citizens of age 40. Could funds from different funding streams be braided together to work toward that kind of objective, he asked.

Mangione-Smith said that “it’s absolutely where we need to be going.... We’re so fixated on cost, length of stay, re-admissions, emergency department visits. I would love for us to start thinking about what outcomes really matter and how do we start to rigorously measure how we’re doing on those outcomes.”

As Jeff Schiff from the Minnesota Department of Human Services pointed out, if prevention and care coordination were viewed as an entitlement in the same way that some medical treatments are, they would be paid for. Better measures and good data could help make the case to policymakers about investing in actions with long-term benefits. As he said, “health care is an expensive way of taking care of social needs.”

## Considerations of Time and Place

Another issue that arose during the discussion period was the influence of time and context on both the social and medical determinants of health. As Lee Sanders from Stanford University pointed out, some children have acute high risk and others have persistent high risk. Furthermore, the same child can require very different care in different places because of the resources available in a given location.

Mangione-Smith pointed to the many different types of contexts that arise even within a given location. Different populations, families, and individuals have different key issues, which affects not only care but screening. Also, as she pointed out, risk stratification has to be done on a regular basis to gauge the effects of change over time.

Feudtner said that positive deviance needs to be studied as well as negative deviance. At the zip code level, for example, people have variance in outcomes as well as exposure. Such a frame orients the conversation to strengths rather than deficiencies, he observed. What enables people to survive and thrive despite the adversities? It might be a father that is holding the family together, or some innate resistance within individuals.

As Hambidge pointed out, partnerships with the community are essential in determining the needs within communities, because “they know the neighborhoods better than anyone and can help us understand the different regional contexts.”

## Session 3: Care Planning and Coordination

Children with medical complexity typically have a variety of needs, which require that they receive care from different sources. As a result, their care needs to be planned and coordinated. These needs often have social and behavioral health dimensions in addition to the more limited medical components. Meeting the full biopsychosocial needs of children with medical complexity can be a daunting task.

Three presenters at the symposium looked specifically at care planning and coordination in the context of medical complexity. Though promising models exist, they observed, many challenges remain.

### Partnering with Families to Support the Integration of Care

Antonelli et al. (2009) have defined pediatric care coordination as “a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.”

These needs can become extremely complex, observed Chris Stille, section head of general academic pediatrics at Children’s Hospital Colorado. He exhibited a care map designed by a parent for an adolescent (Figure 4-1), which encompasses not just medical care but insurance coverage, the home environment, and indicators of well-being. Most children with complex health care needs have maps “at least as complicated as this,” said Stille. “It’s one reason why care coordination is such a huge challenge.”

Parents and guardians are the ultimate care coordinators, and sometimes the only ones, Stille noted. The task of professionals is therefore to support and enhance parents’ roles and to do things uniquely enabled by their training and position. In addition, doctors, nurses, social workers, and community health workers can all address distinct aspects of care.

Care remains fragmented for many families. Yet with the fee-for-service system still predominant, coordinating care remains difficult. In particular, communication among members of the health care team, patients, families, and the community generally remains suboptimal and is rarely if ever reimbursed.

Stille explained differences between care planning, care coordination, and integrated care. Care planning is assessment-driven, created by the care coordinator and family with input from the care team, and needs to anticipate the needs of the patient and family, he said. Using a baseball analogy, care planning is the ball.

Care coordination involves the use of the care plan to respond to needs. For example, a few team members may use care coordination to inform the rest of the team. Returning to the baseball analogy, care coordination is learning to throw the ball.

Care integration is when multiple team members, including top-level clinicians, adapt their care to the changing needs of a child, family, and other team members. Integrated care provides feedback to change the care plan on a regular basis. In baseball terms, care integration is using the ball to play an entire game.

Care plans can be quite complex, and sometimes unnecessarily so. Stille showed one that was six pages and 1,766 words long. Such plans need to be shortened, he said. They need to state the problem, status, activity, responsibility, and time frame for meeting a patient's needs.

Among the members of a team, the care coordinator has unique knowledge and expertise, said Stille. Ideally, he or she has the personality and skill set to be the glue between different components of the health care system. "Doctors, although we try, don't do such a good job of care coordination," he observed. "We have neither the training nor the scope of knowledge about how to coordinate services, although we do what we can."

Care coordination begins with designing a plan that responds to patient and family needs. This requires getting input from the members of a care team to create a useful plan that the members of the team accept. A major challenge is changing the culture of team members to embrace first coordination and then integration of care.

Existing evidence can help drive these changes. Most positive outcomes are from adult populations, and less is known about children with complex health care needs. However, survey data have shown that care coordination has an effect on common outcomes, like emergency department visits and readmissions, and an even greater impact on family-centered care and access to services, Stille said. A limitation of existing data is that most population-level data sources look at services and resources used rather than processes, even though care coordination directly affects processes more than outcomes and it is difficult to relate processes directly to specific outcomes. Nevertheless, data from such sources as the AHRQ Care Coordination Measures Atlas and the CHIPRA quality measures have yielded progress. A related issue is that much of the available evidence is from large programs that include care coordination as part of a bundle, leaving open the question of what kind of care coordination is most helpful under what circumstances. One possible approach to this question, said Stille, would be to develop care coordination-sensitive outcomes that could be examined specifically in the context of children.

The five D's mentioned by Heller in his presentation (see Chapter 2) are also a consideration in care coordination, Stille observed. The two most important are differential epidemiology, since children have a larger number of less prevalent conditions, many of which have a long time course, and dollars, since children with medical complexity tend to be poorer on average and Medicaid differs among states and territories. Because of these factors, Stille recommended taking a non-disease-specific approach to care coordination, with more frequent care plan updates and more emphasis on the social determinants of health, and especially poverty. In addition, a care coordination model that works in one state will not necessarily work in another, given the differences among states.

Families often have multiple care teams, each with its own point of view. Typically, some of the teams are high-functioning and some are not. Some are more collaborative and some are less

collaborative. Each may have a care coordinator, leading families, on a bad day, to say, "I have too many care coordinators. I need someone to coordinate them." In addition, care plans are time-consuming to create and update and often are not reimbursed, and children do not always behave according to the plan. "Even the best-laid care plans are useful most of the time, but not necessarily all of the time. We need to think and do better about flexible care planning."

Another challenge is the transition to adult care. Through research has indicated how to smooth the transition, Stille observed, the problem persists.

Stille suggested some solutions to these problems. One is to designate a primary care coordinator who can be based at a medical home, meet face-to-face with parents, and coordinate across the continuum of care, including among organizations. "This is a hard job, but something like that could work."

Another solution is to provide parent support and training in care coordination. Curricula for training exist and work, he said, and parent-to-parent networks can be used as a tool as well.

Relational coordination is another possible approach, which involves assessing the strengths and relationships of the different care coordinators and taking advantage of those to make a whole. Some forms of care may be based in the care setting, such as a family navigator, while others are based elsewhere, including home visiting, community health workers, peer navigators, or parent-to-parent coordination. The challenge with people who are not based in the care setting is how best to communicate with the rest of the system, Stille said. In addition, innovative resource-intensive care coordination solutions can be hard to generalize and sustain.

Related questions are how to allocate care coordination resources and how to include the social determinants of health in care coordination planning and resource allocation. In response to a question, Stille noted that technologies can help with care coordination, though in many cases "the design isn't quite there yet." He also noted that the patient population seen for primary care at Children's Hospital Colorado is more than a quarter non-native English speakers, while the patient population for the hospital as a whole is not quite as diverse.

Care coordination occurs across sites, which makes reimbursement difficult. Colorado has regional care coordination organizations for Medicaid, some of which provide "delegated care coordination" for attributed children. Such an arrangement can provide for a nurse-level care coordinator for about every 100 children with medical complexity, which is more feasible, said Stille. Other states have payments for care coordination on an ongoing basis.

But who can do care coordination, and who can get paid for it? Parents do the most care coordination, but they do not currently get paid for their efforts. Care coordination also cuts across sectors, which raises questions about how to divide payments and which sector is responsible for payments.

Stille closed with a goal for care coordination:

By 2021, every child with medical complexity will have a care coordination team, including a family navigator and other appropriate non-physician professional(s), to interact with children and families proactively. Their goals will be to support children with medical complexity and their families to promote meeting needs identified by them; promote care integration; formulate, implement, and update a practical, shared care plan; and use services efficiently. The team will be adequately paid for through non-fee-for-service methods that are portable between care settings and payers. And the process will be informed by enough data to determine how much of which services are needed at what time and to enable planning for the needs of other similar children in the population.

“Let’s get started,” he said.

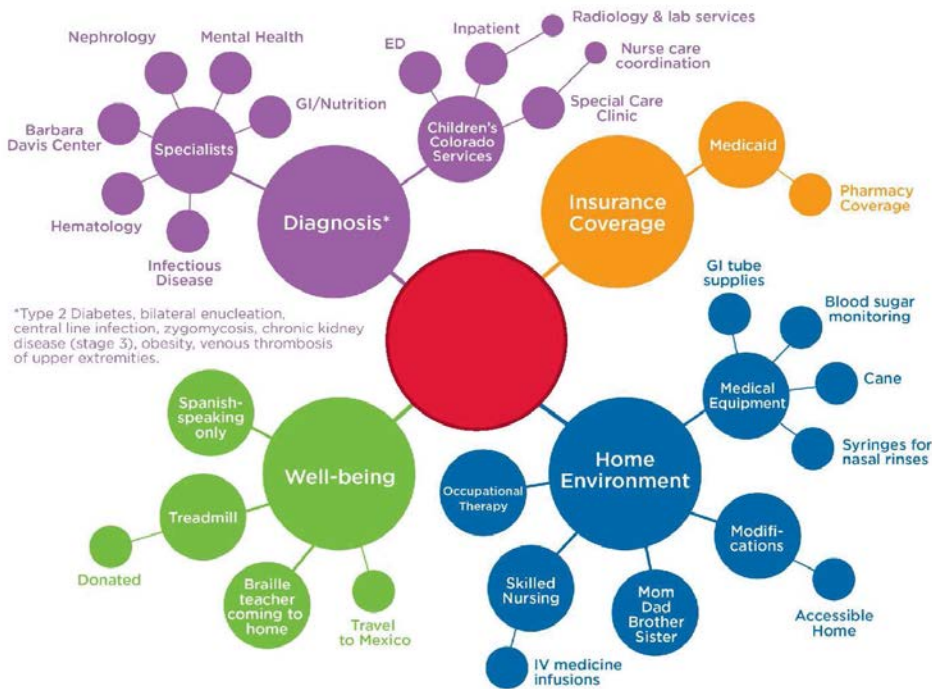


Figure 4-1. Care maps for children with complex health care needs have many components.

## Coordinated Care at Stanford

Stanford Health Care designed a coordinated care program from scratch to meet the needs of the people it serves, said Alan Glaseroff, director of workforce transformation in primary care at Stanford Health Care. The Stanford Coordinated Care program receives a capitated amount of money to be the primary care home of adults with complex medical needs, with the youngest patients being adolescents who are starting to establish independence from their parents.

In describing the program, Glaseroff began by considering terminology. Patients do not identify with terms like “super-utilizer” or “hot-spotter” or necessarily even with “problem.” They do not like the word “manager” because they do not want to be managed. They prefer the word “support,” and “care support” is the term used by the program. Coordinated Care formed a patient advisory committee, prior to finalizing the design of the program in early 2012, that provided helpful advice in choosing terms that better resonated with them.

A major consideration in care coordination is trust, Glaseroff observed, but “it turns out that there's a big trust problem in the U.S.” When patients in 19 countries around the world were asked about satisfaction with their care and trust in their doctors, U.S. patients ranked third in satisfaction with the care received during their last visit to the doctor but 26th in the extent to which they trusted their doctors (Blendon et al., 2014). (By comparison, Switzerland was number one in trust and experience; Denmark was number two in both.) “We're the only country in the world with that gap,” said Glaseroff. “Then we're wondering why the patients are saying, ‘Why are you not giving me that test?’ ‘Why are you trying to restrict what you're doing?’ You can't even begin to have that conversation unless trust is built, and you have to earn trust, you can't be granted it.”

In interviews with 34 Stanford patients with complex chronic conditions, patients said that they often felt alone, more studied than cared for, at the center of coordination, overwhelmed with facts, and passed between providers. “It's not unusual for our patients to have seven, eight, nine, ten specialists.” Their lives were stalled because caring for themselves or a family member was virtually a full-time job, and the costs of their care were an added pressure.

In response to these findings, Stanford Coordinated Care set up a system that begins with a two-hour intake process, an hour of which involves the clinician. This process is designed to identify the domains in which a patient needs help, whether medical, social, mental, or involving self-management or a health trajectory. “We figure out which of these domains are in play and help design a specific care plan around it.”

An activation level is also measured for each patient, from level 1 (starting to take a role), to level 2 (building knowledge and confidence), to level 3 (taking action), to level 4 (maintaining behaviors). About 10 to 15 percent of the general population is at level 1, 20 to 25 percent at level 2, 35 to 40 percent at level 3, and 25 to 30 percent at level 4, though the Medicaid population skews to the left in this distribution.

The Stanford Coordinated Care program focuses on the self-identified goals of the patient and family. The leading questions are “What bothers you the most?” and “Where do you want to be in a year?” That sometimes can mean “biting our tongue,” said Glaseroff, if the patient is concerned about other things than what the clinician considers important. But “if the patient isn't engaged and trusting us, we're not going to make progress on those things, even if we care about them.”

The work is distributed among a care team so that the physician is not a bottleneck to care. The system also uses medical assistants, who “are capable of a huge amount of very effective work, even if they only had a high school degree,” Glaseroff said. “They're often people who, but for



their birth situation and the experiences during adolescence, would've gone to medical school or could've gone to medical school.” These medical assistants combine the roles of coach, advocate, scribe, outreach worker, and population health manager. They stay in the room throughout a patient visit, implying that “this is a member of the team who was part of the crucial conversation.” An important consideration is that these coordinated care workers need more pay, said Glaseroff, so they will not leave for another job.

Based on results with 253 patients with at least six months’ enrollment, the benefits are “striking,” Glaseroff reported. Inpatient admissions are down 29 percent, emergency room visits down 59 percent, reported patient experiences are in the 99th percentile, and Healthcare Effectiveness Data and Information Set (HEDIS) measures are above the 90th percentile. The results also show a movement out of patient activation levels 1, 2, and 3 into level 4 (Figure 4-2). “If you do this right, level 4 goes up precipitously and all the other levels go down.” Particularly for patients who move from levels 1 or 2 to 3 or 4, cost savings can be substantial, said Glaseroff (Greene et al., 2015). Though these results need further study with larger populations, they point in promising directions.

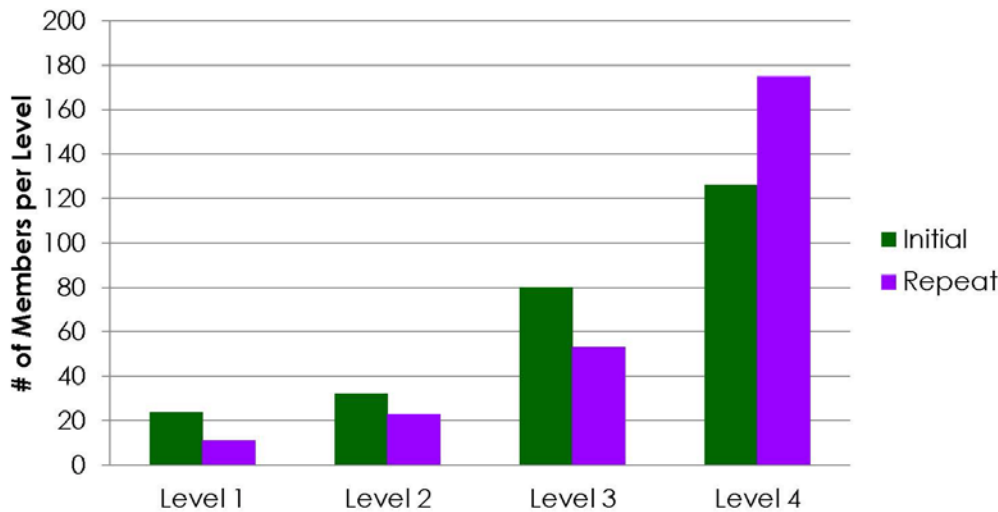


Figure 4-2. The movement of patients from activation levels 1 and 2 into levels 3 and 4 has resulted in substantial savings.

## Putting Families at the Center of Care

In its report, “Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems,” the AAP’s Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee (2014) stated that care coordination should have the following characteristics:

- Be patient- and family-centered
- Be proactive, planned, and comprehensive
- Promote self-care skills and independence

- Emphasize cross-organizational relationships

In his remarks at the symposium, Dennis Kuo, associate professor of pediatrics at the University of Arkansas for Medical Sciences, focused on the first of these characteristics. When care coordination is successful, it addresses care across the entire continuum of health and is driven by the needs of patients and families across a community. At the same time, a family-centered approach is universally regarded as critical for effective care coordination and planning. The question then becomes how to make a care plan most effective given all the different inputs and parts of a plan.

The elephant in the room is the overall health care system, but no one can see and understand all parts of that system, said Kuo. Families probably come closest to seeing all the components, but they are the least empowered to address the issues the system poses. For that reason, working closely with families may be the best way to affect health care outcomes.

Every system of care is guided by a philosophy and supported by an infrastructure, Kuo observed. These attributes in turn reflect a set of values and principles, which, for children with special health care needs, include the following:

- Responsive to family challenges, priorities, and strengths
- Developed in partnership with constituents
- Reflective and respectful of cultural norms and practices of families
- Accessible to everyone
- Affordable to those who need assistance
- Organized and coordinated through collaboration

These principles shape interpersonal communication, facilities, policies, and leadership, Kuo said. They point to the need for open and honest information sharing among parties while respecting and honoring the differences among families. They also place partnerships and collaboration, including negotiation, at the center of the relationship between families and providers. “There are usually multiple ways forward, and to be able to acknowledge that is a huge part of family-centered care,” Kuo noted. Finally, they acknowledge that care takes place in the context of families and communities.

Kuo reproduced some representative quotes from families:

- *I feel like you guys have given me this devastating news that my child has a lifelong disability, and sent me afloat in an ocean and said, “Okay here it is, now go and do something about it.”*
- *No one has ever told me about what is available really. Other parents telling parents is where I get 99.9 percent of information.*
- *We need stronger, more involved case management. We have a hotline for gambling and substance abuse, but nothing for those of us who deal with day-to-day (and sometimes minute-to-minute) airway problems.*

According to the National Survey of Children with Special Health Care Needs, a quarter of families report spending at least seven hours a week coordinating care (Kuo, 2011). Eighteen percent report providing home care around the clock. Fifty-seven percent report financial problems, and “when I talk with my own families about this, they think this is an underestimate,” Kuo said.

According to a recently published study (Kuo et al., 2015), the majority of families in three tertiary care clinics with children who have medically complex conditions are not receiving care coordination, chronic illness management, or help referring to community services or networks from their primary care providers. At the same time, many families face great challenges in planning and coordinating care, including a lack of gas money or transportation, no permanent address, cell phones that are paid for monthly, limited health literacy, being a single parent, having multiple children with special needs, a lack of locally available resources and therapies, and primary care providers who may not be comfortable with management issues. Each of these barriers to care is a leverage point, said Kuo, that can be addressed in improving care planning and coordination.

Innovative multidisciplinary ways of addressing health care needs can be successful. Kuo et al. (2015) also asked families about their health service needs before and after they enrolled in a comprehensive and coordinated health services model. Every single health service need was met in more families after enrollment (Table 4-1). Even respite care, which was not specifically provided by three tertiary care clinics in the study, went up. “We do not say that this is the only model that's possible,” said Kuo. “There are scalability and cost issues to be addressed. But I do think we may be on to something when we talk about a comprehensive multidisciplinary team-based approach to care.”

Kuo urged providers to respect families, refrain from judging, and not use labels. “I don't ever want to hear the words ‘problem parent’ or ‘difficult parent,’” he said. “It establishes a lack of partnership being able to go forward.” He advocates the use of person-first language—child with autism, not autistic child. This behavior needs to be modeled for staff and associates to establish a family-centered relationship, he said.

Additional steps include implementing tools and templates that increase family participation, developing families as advisors, and assessing family needs on a routine basis. “This is more than saying we're going to have a number of family focus groups. This is about having families at the table as colleagues.”

Parents can be taught to be effective advocates, he observed. They can learn what the ideal health care experience should be, expectations for care planning and coordination, the tools that are available, and the family networking and support systems to which they have access.

The principles of family-centered care can define the system for care planning and coordination, Kuo concluded. They can inform the structures and processes necessary to develop the system, improve and streamline care delivery, and create the culture that is necessary to effectively coordinate and plan care. In that regard, Kuo left the symposium participants with three questions:

- What is your culture of family-centered care?
- How well do you incorporate family advisors and partners?
- How well do your tools, alerts, and reminders incorporate family-centered care principles?

## **The Composition of Care Teams**

A focus of the discussion session was the composition and roles of care teams, since care coordination inevitably reflects these attributes. Stille began by emphasizing that the expertise of the team needs to cut across care settings, which also requires coordinated policies and payment structures. “Unless we achieve that relational coordination, things are going to be fragmented.”

What is the best way to integrate behavioral and mental health professionals into care teams? Given the ubiquity of mental and behavioral health problems in the patients they see, Glaseroff and his colleagues at Stanford have embedded a licensed clinical social worker into their care teams, who largely does what he called “trauma-informed care.” “Our job is actually behavioral health,” he said. “The medical stuff is almost trivial in the mix very often, except at rare moments.”

On this point, the facilitator of the session, David Labby of Health Share of Oregon, pointed to the importance of community mental health services. The population of deinstitutionalized patients requires many of the same services as patients with special health care needs, he said, which reflects the growing recognition of the links among physical, mental, and behavioral health.

Particular interest centered on Glaseroff’s mention of medical assistants taking on a different role for care coordination. In response to a question about how to keep medical assistants from devoting all their time to other tasks, Glaseroff said that the medical assistants in the Stanford Coordinated Care program spend about half their time doing things other medical assistants do, such as drawing blood and giving immunizations. But because they stay in the room throughout the visit, they learn about the patients even as the patients are not forced to go elsewhere for procedures. Not every medical assistant wants to or can do this job, but Glaseroff and his colleagues “hire for empathy,” he said. “We put word out across the managers of the different clinics, ‘Send us your people who are getting in trouble for doing too much.’” For example, the first person they hired was a woman who grew up in New York City and was one of nine children to a woman who also cared for another five foster children. “She is an amazing balance of wisdom, smarts, practical, and totally driven to get her work done.”

Stille added that the patient population at Children’s Hospital Colorado is more than a quarter non-native English speakers, and the medical assistants are the members of the care team most likely to have the culture and language ability to connect with those patients. “We’re learning now, little by little, how to integrate them and take advantage of their many resources and abilities.”

## The Roles of Families

The other major focus of the discussion was the roles that families assume in care coordination. As Eileen Forlenza of the Colorado Department of Public Health and Environment pointed out, most families need training to serve as advisors in systems of health care, yet professional development institutes and leadership opportunities for families are not funded as well as they should and could be. If greater activation of families and patients is needed, “why doesn’t it show up in any of our budgets,” she asked. “Why can’t we say in every presentation we do with family-centered care that families have to be co-presenters? Then what does it take to pay for those families to attend, because they’re leaving their day job as a school teacher, or a lawyer, or a restaurant owner?”

Integrating families more firmly into care requires a culture shift, Kuo responded. “I don’t think we’ve invested enough in the training or the orientation or the expectations for families,” which is something that will be required to change the culture. Another option is to take advantage of parents with experience in these issues, even if they are not the parents of current patients.

Another aspect of culture change, noted Lisa Rossignol from Parents Reaching Out, would be for policy deliberations always to involve a patient or family. “The benefit of having families [involved] is that they’re not indoctrinated in systems,” she said. “When you’re going to do any initiative, find a patient or a family member and ask for their input. Not just a focus group. Not a survey. Ask them. Have a conversation.” Michael Harris from Oregon Health and Science University also suggested treating parents as capable of having such conversations, which is a simple thing that can be done to improve the quality of those conversations.

Glaseroff pointed to the value of training patients and paying them a stipend to participate in a health care system. In one collaborative project in which he was involved, the parents met the providers the night before each meeting and led off the session with a skit or a story. “You could see the providers’ jaws drop. Then the meeting went well every time. It’s transformational”—so much so that the collaborative made such parent meetings mandatory. Kuo added that some research has looked at the role of siblings in families taking care of children with medical complexity.

Finally, Daniel Armstrong from the University of Miami Miller School of Medicine reminded the symposium participants that families are extremely heterogeneous both among and within families. Combined with a severe workforce shortage for children’s mental health services, the variety of families points to the need to train providers to a new care model, to which Stille cited the benefits to be gained from an all-teach, all-learn and large-team approach to training. “Many medical schools are [using] patients as teachers, which was certainly not the case when I was in medical school 25 years ago,” he said.

## Session 4: Supporting Self-Management

For children with complex health care needs, self-management is a necessary component of care and one that increases over time. Self-management is built on trust, hope, and expectation, said the facilitator of a panel on self-management, Judy Palfrey of Boston Children's Hospital. It requires a different perspective on health care, where providers do as much listening as talking and accompany patients through their journeys rather than leading them. But the health care system is not currently structured in such a way as to optimize the benefits of self-management.

### Self-Management in Children with Chronic Conditions

Children with chronic conditions constitute a larger group than children with complex health care needs, but the lessons learned can translate from the former group to the latter, said Paula Lozano, senior investigator with Group Health Research Institute in Seattle.

Most research on self-management for chronic conditions has looked at adults, not children, but pediatric self-management is different from adult self-management, Lozano said. With adults, interventions to support self-management can include engaging them in self-monitoring, helping them adhere to elements of a care plan, providing them with behavior change counseling, and helping them with goal setting and problem-solving. With children, the same principles apply, but the circumstances are different. Parents may want a child to adhere to the medication regimen, "but the child may have other plans," said Lozano. "Who is supposed to remember to pack the inhaler for a sleepover? Are there meal times battles? When you talk about goal-setting, whose goal is it?"

Pediatric self-management also undergoes a trajectory, she said, from the child or adolescent depending fully on the parent or caregiver, to a situation of increasing autonomy, to, in some cases, independence with a limited role for a parent or caregiver.

With support from the Lucile Packard Foundation for Children's Health, Lozano and her colleagues have investigated self-management for children with chronic conditions, which she defined as what happens outside of the health care setting. They began with a literature review to identify theories that address pediatric self-management, dividing the theories along four dimensions: the individual, the interpersonal, the environmental, and the temporal. Theories that emphasize skills, self-efficacy, self-determination, and social cognitive theory tend to emphasize the individual. With pediatric self-management, these considerations apply both to the child and to parents.

At the level of family relationships, people live in interconnected and interdependent systems. For example, family systems theory emphasizes these interpersonal webs of relationships to understand self-management, with a particular focus on bi-directional relationships between parents and children.

A third set of theories emphasizes the social determinants of health and socioecological models. In these theories, multiple players and institutions exert effects on the capacity for self-management.

The fourth set of theories highlights the temporal progression from a child providing some self-care, to managing and supervising his or her own care, to becoming “CEO” of self-management, with the parent transitioning from the supervisor to self-management consultant.

Lozano and her colleagues put all four of these dimensions together to produce a comprehensive theory of pediatric self-management. In this theory, the parent role diminishes over time, though it may persist for an extended period, depending on the child’s circumstances.

Lozano also described some of the focus group work that her team has conducted. The focus groups involved ten mothers of children ages 5 to 17 with chronic conditions and six women and two men between the ages of 18 and 25, also with chronic conditions. Only one had multiple chronic conditions, so participants did not necessarily have complex needs, but their comments are nevertheless applicable more broadly, she said.

For most families, self-management gradually shifts from parents to children, but many parents are ambivalent about this shift. On the one hand, they want their children to develop skills and be confident and unafraid. On the other hand, many were afraid for their children: “What would happen if I wasn’t there or if I didn’t take care of something?” “He’s too young to do this.”

Lozano quoted some of the parents and young people verbatim. This mother of a 13-year-old boy with multiple chronic conditions said, “I’m more the helicopter parent, like being careful about summer camps. He went to Crohn’s camp last year; it’s highly monitored by physicians and other people who are trained. I think I’m more cautious with him. I’m looking forward to college, too, but oh my gosh, I might have to move to the town he is in just to be there. What if he has a seizure?”

The mother of a 14-year-old with diabetes said, “You want to trust them because they are responsible. They take care of themselves usually, but it’s just nerve-racking. It’s hard to give them the independence they want and still let yourself take over the care that they need.”

The mother of a 13-year-old girl with severe asthma said, “She gets up in the night sometimes, and I don’t even know she is on the machine until I hear it. She will be like, ‘Mom, mom’ where she can’t really get up, and I’ll say, ‘I’m right here, what’s wrong? What’s wrong?’ Other times she is like, ‘Just go away please. I can do this.’”

An 18-year-old woman with type 1 diabetes said, “There are a lot of things about diabetes that you have to transition into when you’re taking care of yourself.... A couple of weeks ago, I started putting my insulin pump in myself, by myself. I was at school and my pump stopped working, and my mom is like, ‘Yeah, we can’t come help you. You’ll have to do it yourself. Plus, you’re going to college in a couple of months. You’ll have to figure it out now.’”

A 20-year-old with muscular dystrophy described getting pneumonia when she was going to college five hours away from Seattle. She said, “My parents were here in Seattle, and the campus health clinic said, ‘Well, it’s possibly pneumonia. If anything gets bad, you might want to go to the ER just to be sure, you never know. Your lungs aren’t as strong because of the dystrophy. You want to be on top of this.’ I wasn’t feeling so great so I went to the ER just to check things

out. I had to deal with insurance and explain my medical history and deal with it on my own. My parents called and asked, 'Do you want us to fly out there?' And I'm like, 'Well, you can't really do anything. It's okay.' It was like kind of pandemonium, transitioning to taking care of my own health."

The need for coaching of young people transitioning to self-management was a common theme of the focus groups. For example, the mother of a 13-year-old boy with diabetes said, "There was one time recently when he came home and his blood sugar was a bit high and I said, 'What did you have to eat?' He said, 'Well, I had an ice cream at school, but it's got the nutrition information on the package. I know there's this amount of carbs in it, so after I had my lunch I did it on the pump.' I thought he thought I was going to be mad at him, but I said, 'Well, that's wonderful. I'm glad that you feel like you can eat this and you're going to do the right thing for it. I think it's fantastic that you're getting more comfortable with it and taking responsibility for it.'"

The young adults also perceived the value of coaching. A 20-year-old woman with debilitating migraines described staying up at night as a senior in high school and realizing that her parents could not also stay up late. She said, "I had to make the choice, and I wasn't going to wake up my mom and go, 'What should I do?' I just have to be able to figure out this stuff on my own." A woman with panhypopituitarism described her father modeling for her how he dealt with pharmacy and insurance issues and then handing it over to her. "He wasn't helping me much. Only a little bit. It's been difficult, but seeing what my dad has done, I have that routine."

Part of coaching is allowing children to fail, Lozano noted. The mother of a 16-year-old boy with asthma said, "I think letting them fall a bit, knowing the safe distance to let them fall, like playing basketball and not bringing your inhaler and realizing and calling to their attention that they're in really bad shape."

The alternative to coaching and letting children fail is not having a plan, Lozano said. For example, the mother of a boy with multiple chronic conditions said, "It's hard to put a baby monitor on a teenager, for many different reasons.... I don't have him on the monitor now. I just have to say some Hail Marys at night that everything will be okay."

Lozano and her colleagues have used the results of the focus groups to generate hypotheses and ask questions about the transition to self-management. "The families in our focus groups clearly understood that there was a trajectory toward independence, but there is a great variety of ways of getting there and letting go." In general, the transfer of self-management tasks from parent to youth is much like parenting, "only more so," said Lozano. "It's the same as teaching toilet training, homework, chores, crossing the street on your own. It falls into that same model. It's just different content."

Lozano left the symposium participants with several questions involving future research:

- What would the care of children with chronic conditions look like if it explicitly addressed the different dimensions of pediatric self-management—self-efficacy and autonomy, family systems, the social determinants of health, and the shift of responsibility from parents to children?



- What would be the implications for assessment, care planning, and the development of interventions?
- Should self-management be framed as a facet of parenting?

In response to a question, Lozano pointed out that working with patients and families on self-management takes time and effort. “We need to be thinking about self-management support work as a team function, involving nurses, medical assistants, social workers, physical therapists, case managers, care coordinators, and others. It’s not a single provider who is supporting families in this way.” When self-management becomes part of the conversation, it can become both ongoing and sustainable. “Who does what in your family? How does your family system deal with the tasks of self-management? How do you think she is going to be managing her illness tomorrow? How do you think things might change for her over the coming year—and how can we help her rise to that challenge?”

## Supporting Self-Management

The objective of rehabilitation is to optimize the health, function, and well-being of children with disabilities, said Amy Houtrow, chief of the Division of Pediatric Rehabilitation Medicine at Children's Hospital of Pittsburgh, and self-management is part of this development. Not all children with complex health care needs can self-manage, but many have the agency and autonomy to direct their own care. “We see it in the young child trying to assert their will, and we see it in the teenager who is asserting their will by perhaps not adhering to treatment protocols.” Self-efficacy, self-determination, self-care, and self-discovery are all part of becoming “the owner of your health over time,” Houtrow said.

Self-management involves much more than just the medical care setting, she explained. “We need to be holistic and recognize the inputs from very different sectors of the world into our health care setting.” Physicians sometimes blame patients for a lack of adherence to a treatment protocol or a follow-up failure, but they need to remember that “the realities of life fall so far outside of the realities that we see in our settings in health care.”

Any difficult or complicated task requires training, practice, and building capacity. A typically developing three-year-old eventually will learn how to get dressed in the morning, but a child with functional limitations needs consistent effort and attention to the minutiae of the steps to develop that skill. Accommodations may be necessary for success, but developing capacity through repeated performance is also necessary to build complex skills. “We need to pay attention to understanding competence.”

Competence depends on an interaction between people and their environments, including the social environment. The woman who has to work a 12-hour shift without much food in the house and is on a warning from her boss that she will not have a job if she shows up late is in a different situation than other mothers, but “that is the reality of a lot of our patients,” said Houtrow. Sometimes developing self-management skills cannot be a family priority. “We’re talking about a quarter of children living in poverty, we’re talking about those families being

food insecure, not knowing where their rent is going to come from, not knowing if they're going to have a home next month. We're talking about a lot of barriers to successful autonomy in self-management." As an example, Houtrow told the story of the eight patients she recently cared for on her pediatric inpatient rehabilitation unit. Of these children, three of them had mothers in jail and four others were actively involved with child protective services. The last appeared to be from a fully functional and intact family, but when Houtrow asked the child's mother, "What brings your child joy?" the woman collapsed into tears. She "was on the verge of not making it, and we needed to mobilize everything that we could for her well-being because that was going to impact her child's well-being." Sometimes, focusing on the here and now is the necessary thing to do, said Houtrow. The risk is losing sight of promoting independence and self-management when faced with the dire circumstances that children and families experience.

Both children and families can have a variety of limitations contextualized by the worlds in which they live. Similarly, some activities are straightforward, and others are very complicated. Houtrow laid out a hierarchy of proficiency ranging from novice through advanced beginner, competent, proficient, and expert. "I was a child with complex health conditions. I've had them all my life.... [But] even I don't feel proficient or competent a lot of the time. We have a system that is set up to make it so challenging that you can't actually achieve a high status of expertise." As an example, Houtrow cited a recent experience providing care coordination when the child's care coordinator fell sick. The child, who had multiple chronic conditions along with a brain tumor, had a mother in jail and a cousin who had just tried to commit suicide. "It took me 2-1/2 hours and nine phone calls! It is scary that I can't feel like an expert, even though I have all the tools that should make me an expert."

Care providers need to be cognizant of families' circumstances and what is important to them, she said. "Maybe self-management right now isn't the top of the list. Maybe it's about just getting by. That's an important aspect of family-centered care. We place the family and the child at the center of what we're doing, but what we need to do is make sure that we're navigating their needs with them." For example, in response to a question, Houtrow pointed to the inconsistency of not letting patients take their home medicine at the hospital and giving patients prescriptions as they leave. "That's completely unreasonable. That's not a good way for us to teach you and engage in a process of feeling capable of doing a task once you get home." With inpatient rehabilitation at her hospital, families have training goals to take over higher degrees of managing care, and for the last two days the patients and families have their medicines in hand and are expected to administer those medicines themselves. This helps develop skills and confidence.

With regard to self-determination and efficacy, Houtrow said that children and families need opportunities to fail, but they also need opportunities to succeed. Taking good medical care of a child can be very important to a family, and promoting independence can sometimes run counter to this priority. This requires stronger communication, respect for peoples' differences, and engaging all parts of a care team. For example, Houtrow's institution has been doing parent-based problem-solving skills training, and because it is directed by what the family wants, it can be very empowering. "The parents get to decide. They get to address the issues that they want to address. This model is very successful."

Houtrow concluded that “we need to meet families where they are, help them develop tools that they might not have, access resources that extend well beyond the health care setting, and develop and promote autonomy and self-efficacy.” She also noted, in response to a question, that self-management is part of the rights of children, as laid out by national legislation and international conventions.

## **Lessons from Adult Self-Management**

Self-management among adults offers valuable lessons about self-management in children and transitions during aging, along with practical tips about getting people more involved in the design and improvement of care, said Susan Edgman-Levitan, executive director of the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital.

The team models discussed by other presenters are critical, she said, because they help decrease both the time pressure on physicians and the hierarchy between providers and patients, who “may feel much more comfortable talking about things that they don't necessarily feel comfortable talking about with physicians.” Physicians may be less willing than other care team members to let a patient or family member talk about what they have experienced and what concerns them.

Providers tend to worry about the knowledge that they have to pack into patients and family members, but “it's much more than knowledge,” said Edgman-Levitan. Patients need confidence, determination, and all the other attributes mentioned by the other speakers on the panel. Other patients with their conditions are often the best teachers, she said. In self-help and support groups, when patients set the agenda, they generally cover everything a provider would want to cover. However, patient-instructors “are still not built into the mainstream of care, at least not in my world,” often because of reimbursement issues and the logistical issues of bringing people together.

In an intervention required as part of the NCQA PCMH recognition program, patients who had chronic conditions across the Partners Healthcare System, with asthma and ADHD in pediatrics and depression, diabetes, and hypertension in adult care, were required to have a care plan, including patient goals, in each person's chart. “To me this is a lynchpin about education and engagement,” she said. It minimizes what she called “almost pathological magical thinking—where we tell people to do something and therefore they're healed, we're all done, we don't have any more responsibility.” At first physicians were resistant to discussing goals with the patient, but when they began doing it, “they were stunned,” said Edgman-Levitan. “They had no idea what their patients' goals were, and the way that patients framed their goals was entirely different from the way that the physicians were thinking about it. One of the physicians in our geriatric practice had an elderly patient who really needed to lose weight. Every time this person would come in, the doctor would say, ‘Okay, you've really got to lose 10 pounds.’ Then he decided to ask the person, ‘What do you care about?’ and the patient's response was, ‘Well, I think my goal should be, instead of having five meals at McDonald's every week, I'm going to have four. Let's start there.’ That was a real eye opener for the physician. It never occurred to the doctor that this is how this person was eating. Now they had a place to start.”

Another eye-opener, according to Edgman-Levitan, was how few health care providers had training in motivational interviewing. Of thousands of physicians and nurses in the Partners Healthcare System, only five people had gone through formal motivational interviewing training and felt confident in their skills to teach others, “and you can imagine, they were completely overwhelmed with the demands for their time.” This is a competency that needs to be developed in all health care professionals, she said, starting early in professional education.

Edgman-Levitan agreed with Houtrow that patients need access to their own medical information. When patients can read in plain language about their own care, “we give them at least a fighting chance to understand what's going on with their health, what's going on with their care coordination, and what they can do to make a difference.” She also pointed out that adult health care providers have not been prepared to interact with the empowered and engaged families that they increasingly are seeing in their practices. “They're used to taking care of elderly patients who often have families that live afar and people who have not learned to advocate for themselves,” she said. “This is going to be a whole new universe.”

A related issue, noted Edgman-Levitan in response to a question, is how to fund greater patient involvement and self-management. She and others have been largely unsuccessful getting funding from government agencies or foundations to enhance patient and family involvement in care redesign or improvement work, leaving only individual donors as a source of support. People need to be paid to do this work, but what mechanisms can be used to do so, she asked. One possible approach is the one taken in Massachusetts, which legislated the creation of patient family advisory councils at every hospital as part of health care reform. Care teams also will be more successful if health coaches or exercise physiologists are available, she said, though they may not be able to contribute if they cannot be reimbursed.

Edgman-Levitan offered several practical points for selecting patient and family representatives. They need to be good communicators, pay attention to other points of view, and know how to deliver criticism constructively, she said. They need to have the right experience of illness for the task and “hopefully have a good sense of humor.” She also recommended naming representatives for one-year terms so that they can be gracefully dismissed if the fit is not right.

Patient education materials and self-management tools need to be reviewed by patients and families to make sure that patients understand them and that they focus on the topics of relevance for the patient and family. She often finds educational materials that patients have left behind or discarded. “It's not end user failure,” she said. “It's design failure on our part.”

The best approach, she concluded, is for providers to move the focus “from what is the matter with you to what matters to you” for patients.

## **Respecting Cultural Differences**

A topic that arose during the discussion session involved the great and increasing diversity of families interacting with the health care system. As Nora Wells from Family Voices observed, families from a great variety of cultures need care, even though many health care strategies are geared toward white middle class patients. It takes more time and money to develop leadership

from more diverse communities, she observed, because expectations are not the same and people need more time to understand the system. “We have to put the resources in the area that’s going to help some of the more diverse families take a role.”

Edgman-Levitan recounted an experience in Massachusetts where focus groups done in Cambodian and Spanish on the completion of health care proxies resulted in approaches that were entirely different than the approaches used previously. “We have to apply the same patient involvement in how we design what we’re doing, no matter what population we’re talking about.”

The point was also made that training to deal with issues of self-management, especially in a diversity of cultures, needs to start early in medical school. According to facilitator Palfrey, new training programs are producing a diverse and enthusiastic generation of providers. “They’re ready. What’s not ready is the payment systems that are needed to support them.”

## Session 5: Models of Co-Management and Team Care

Given the complexity of providing care for children with complex health care needs, a multilayered system is necessarily. Such a system blends health care providers, members of community organizations, families, and patients themselves. However, this combination of actors needs to be coordinated as a system to ensure the coherence and efficiency of care, noted the speakers on a panel focused on models of co-management and team care.

### The Need for Co-Management

Primary care providers may feel uncomfortable caring for children with medical complexity for a variety of reasons, observed Timothy Ferris, senior vice president for population health management at Partners HealthCare in Boston. They may lack specialized knowledge or be unfamiliar with various community, governmental, and educational resources. They may not have the time or personnel to develop and maintain relationships with organizations. They may worry that such children would consume a large amount of a practice's resources for chronic condition management and care coordination, even though children with medical complexity need a medical home and primary care services.

In addition, the care coordination skills needed for children with medical complexity differ from those needed for children with chronic conditions, Ferris pointed out. Caring for children with medical complexity requires greater communication with medical specialties, schools, and specialized educational services and community agencies. In addition, transitioning children into adulthood may involve such issues as the legal complexities of guardianship, alternative living arrangements, and finding adult physicians comfortable with caring for these childhood diseases in adults.

As a result of these difficulties, co-management and team care are vital in caring for and supporting children with medical complexity, said Ferris. Such care may require a variety of medical services, including:

- Hospital-based specialty care
- Pharmacy supplies
- Home health care supplies
- Outpatient and rehabilitation programs (such as speech, physical, and occupational)
- Mental health services
- Palliative care services
- Home nursing programs/patient care attended programs
- School nurse/school-based medicine

It also may require a wide range of community services, including:

- Respite care
- Medical child care services
- Special education programs/out-placement schools

- Child care options
- Supplemental Security Income support
- Title V programs
- Palliative care programs
- Community- and foundation-supported activities and services
- Sibling and parent support groups
- Specialized play groups or adaptive physical activity programs

The challenges to providing these support services are numerous, Ferris continued. They include complex networks of state and local government agencies; differing enrollment criteria, costs, service delivery capacities, and so on; the changing availability of resources over time; and difficulty gaining enough knowledge about each service and keeping up with changes.

Current models of care coordination, each of which has its own strengths and weaknesses, include hospital or specialty-based programs, state-level case management, care coordinators employed by a single primary care practice, and care coordination provided by integrated health care delivery systems via contracts with insurers (Table 6-1). At Partners HealthCare, the pediatric high-risk care program, which was launched in 2013, is staffed by one clinical manager and five care managers, two social workers, a medical director, and a pediatric psychiatrist. It includes a web-enabled dataset that allows any practitioner to search for community support services by zip code under 15 categories of services.

Making the business case for these approaches is important, Ferris said. Savings in the health care system may include decreasing preventable morbidity, decreasing emergency department and hospital utilization, and savings from less duplicative care and gains in efficiency by primary care providers. Savings outside the health care system can include better student achievement and parents who are more fully employed, more productive at work, and able to spend more time caring for their other children.

This approach has provided a large return on investment from care coordination work done with the elderly, which has been used to fund care coordination for everyone else. However, Ferris noted that, while he has good data on returns on investment for adult patients, he has not been able to find evidence for a positive return on investment to health care managers or payers for children. “That doesn’t mean that it isn’t producing better outcomes,” he said. “We are seeing phenomenal improvement in satisfaction and decreased stress among parents.... You could provide all the care coordination possible, but if the mom or the dad is too stressed to function, they can’t follow through with the management plan no matter what kind of supports we try to provide for them.”

What would help make the case to managers and insurers is data from an annual cohort derived from all payer databases at the state level that tracked the sickest patients and their cost trends over time, said Ferris. “This would be an important policy lever, and it’s not hard to do from a technical perspective.”

Model	Service strengths	Service challenges
1. Hospital- or specialty-based program for children with medical complexity	<ul style="list-style-type: none"> <li>• Providers have inside knowledge of services within the hospital</li> <li>• Ease of communication between program and specialists</li> <li>• Option to provide inpatient services</li> <li>• Staff have expertise in medical complexity</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of natural connection to primary care</li> <li>• Lack of connection with local community resources, since programs likely draw from a large geographical area</li> <li>• Some patients likely travel long distances to hospital for appointments</li> <li>• Perverse incentives for hospital to fund such a program if it results in decreased utilization of hospital services</li> </ul>
2. State-level case management	<ul style="list-style-type: none"> <li>• Case managers specialize in medical complexity</li> <li>• Knowledgeable about public programs/resources</li> <li>• Can provide care across payer spectrum</li> <li>• Potentially more oversight by public/patient groups</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of natural connection with primary care and specialty providers</li> <li>• Potentially inflexible enrollment criteria that is set by the agency</li> <li>• Less knowledgeable about private community resources</li> <li>• No business case for privately insured patients</li> <li>• Little ability for electronic record sharing with primary care</li> <li>• May have limited knowledge of medical complexity</li> </ul>
3. Care coordinator employed by a single primary care practice	<ul style="list-style-type: none"> <li>• Strong connection with primary care practice</li> <li>• Care coordinator can serve other family members if also seen in the practice</li> <li>• Familiarity with local community and able to develop personal relationships with agencies to facilitate referrals</li> <li>• Primary managed by practice so can change depending on practices' needs</li> </ul>	<ul style="list-style-type: none"> <li>• Less familiarity with state and hospital-level programs targeted toward children with medical complexity</li> <li>• Unless practice is large, may not have the volume to maintain expertise and relationships with programs/entities that serve children with medical complexity</li> </ul>
4. Care coordinator provided by integrated healthcare delivery system via contract with insurer	<ul style="list-style-type: none"> <li>• Strong specialization in issues related to complex care</li> <li>• Ability to see all claims/utilization and track over time</li> </ul>	<ul style="list-style-type: none"> <li>• Less connection with primary care, especially if practice has only a few patients with certain insurer</li> <li>• Less connection with tertiary care, community programs and agencies</li> <li>• Little oversight/influence by patient</li> </ul>

Table 6-1. Strengths and Challenges of Current Care Coordination Models

## A Primary and Tertiary Care View of Co-Management

The essential systems in primary care medical homes for co-management in chronic conditions can be summed up in seven R's, said Jennifer Lail, assistant vice president for chronic care systems in the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital:

- Relationships
- Ready access
- Registry, care coordination, and planned care
- Records (electronic)
- Resources, internal and external



- Reimbursement
- Recruitment

After working as a pediatrician in private practice for more than three decades, Lail came to Cincinnati Children’s Hospital to work on a quality improvement initiative, but she also works one day a week in the complex care clinic. What she and her colleagues have found is that the list above applies in the medical center, too. They have been working with condition-specific teams at the hospital to build the components of the chronic care model into their support for families. They have registries for population management within the electronic health record that are very helpful for data collection. They also have been measuring and improving clinical, functional, and patient-reported outcomes for children—for example, using electronic tablets to have families report on their quality of life. Medical and psycho-social risk stratification and pre-visit planning have helped identify the “sickest of the sick” to anticipate patient and family needs. Parent advisors work with the quality improvement teams, and “there’s been many a meeting where a parent has changed the whole trajectory of the meeting,” said Lail. All of these foundational pieces help with co-management, she said.

The initiative has been changing attitudes to embrace a “culture of collaborative care,” she continued. Allies and resources can be identified and connected personally, electronically, and across domains. Information about “what do I need to know to care for this child” can be communicated explicitly. The roles and responsibilities of the medical home, specialists, families, and other partners can be clarified and rationalized. Care beyond the encounter can be supported. As Lail observed, “The child spends somewhere between 20 minutes and an hour with us, and they spend the rest of their lives outside the hospital.” Finally, this new culture can focus on the unique needs of children with medical complexity. “I have a toddler who has a G-J [gastrostomy-jejunostomy] tube, a central line, and a home ventilator. He walks, and I chase that child around. I couldn’t have taken care of him in my community-based primary care practice, so we have to recognize that we need a special place for children with medical complexity.”

Systems of care also require population registries that are stratified by need, bi-directional electronic communication, and “person support,” said Lail. “We build so many wonderful tools and they’re great. But you have to have processes and you have to have people to use those tools.” Data on outcomes, value, and funding can support change. Finally, incentives should encourage partners to “do the right thing,” including standardizing common processes, providing decision support, developing algorithmic care for triage and follow-up, and committing to accountability.

Lail concluded by listing the steps that must be taken to co-manage care:

- Know patients and populations
- Communicate explicitly
- Partner with families
- Work as a team, optimizing all skills
- Make a care plan and choose a plan leader
- Empower and improve through “all teach, all learn”

- Share resources in the medical neighborhood
- Give evidence-/consensus-based care at the most appropriate site
- Measure and improve outcomes and spending
- Innovate to build a patient-centric system

As Lail pointed out, care for children with medical complexity can pose great difficulties to families in some setting, such as rural areas. In such cases, it may be necessary to develop co-management programs with complex care centers even if they are at a distance.

## **The Lessons from Geriatric Care**

Finally, Peter Boling, chair of the Division of Geriatric Medicine at Virginia Commonwealth University, provided a perspective from someone whose work has centered on geriatric education and on improving care of people with advanced chronic illness. The patients that he managed in his geriatrics practice need an advanced medical home that is truly patient-centric. That may mean that they need mobile health care, which is why he has been making house calls for more than three decades. “You need to go to the patient's home when they're not very mobile or when they're having unexplained and recurrent utilization problems that you can't sort out in the clinic,” he said. If you don't go to the home you're never going to get it right, because you're missing half the story when you try to do it from the clinic.”

Boling began making house calls when he saw patients on stretchers or in wheelchairs when they came to the clinic and asked them whether they would like him to come to their homes rather than coming to the clinic. “Nobody ever turned me down,” he reported. In the process, he began to see the world differently.

“What my colleagues at the hospital thought was going on was, most of the time, wrong.” Many of these patients had poor access to care. They were relatively immobile and they needed help getting to the clinic, but help was not always available when they could make an appointment. Their care was not coordinated or continuous, and lapses in care plans could occur in medical centers. Boling became convinced that greater use of house calls could reduce the use of the emergency room, decrease hospitalizations, shorten length of stays, decrease, and improve outcomes for patients. But when he started trying to convince his colleagues, they said, “That's great, except we get paid next to nothing for doing this.”

Years of advocacy with the Medicare program did lead to an increase in rates for home visitation. But this support did not cover team care, including social workers, nurse coordinators, and other professionals who cannot bill for their services in the same way. “Those other people have no mechanism for being paid under fee-for-service,” he said. “If you're going to have a team, you have to have a payer source.”

During a home visit, a care provider can discover and accurately evaluate a patient's most important problems, said Boling, quoting a colleague who said, “The only true medical reconciliation is done at the kitchen table.” A provider can understand the needs and capabilities

of a patient and caregivers, including the patient's functional and cognitive status, environmental safety, and social support. "There's no source of that information other than going to the home."

Partners are essential to a core house call team, Boling said, including social service agencies, home health agencies, personal care agencies, nursing homes, hospital and specialist physicians, pharmacies, mobile X-ray and laboratory services, and curable medical equipment providers. "These resources are around us in the community. We all know about them on our house call team, and we use them."

Eventually, home visits need to be justified financially, he said, and "there is evidence for the house call model." Naylor et al. (1999) showed a 50 percent cost reduction in adults through a randomized controlled trial of home visits. Brooten et al. (1986) demonstrated earlier discharge in a pediatric population. Edes et al. (2014) found a 15 percent reduction in risk-adjusted costs among veterans, with the biggest impact in the sickest patients. De Jonge et al. (2014) found similar results in non-veterans.

On the basis of these results, Boling and his colleagues proposed a house calls team model to Medicare known as Independence at Home. They guaranteed minimum savings of 5 percent, with a sharing of savings above that amount. "The results have been good," he reported. The program produced savings of more than \$25 million on 8,400 high-cost beneficiaries. "We got a check for \$1.8 million, which helps to support a team-based approach."

The same approach could be successful with the right population of children, Boling suggested.

## **The Power of Relationships**

Commenting on the emphasis on relationships at the symposium, Francis Rushton of South Carolina Quality through Technology and Innovation in Pediatrics said, "I've never been to a meeting where I heard this word used so many times. I really do think that the relationship, not only between the health care provider and the patient, but between the whole health care team and the patient, is a primary determinant of how that patient feels about their functional health."

Ferris pointed out that a meta-analysis from the Congressional Budget Office looking at disease management programs found that the greatest effects tended to come from programs with embedded care coordinators. In these programs, the care coordinators knew the patients rather than being a disembodied voice on the telephone, which also argues for the power of relationships.

Relationship development is critical, Ferris argued, which has several key implications. It affects the steps taken to deal with staff turnover, the distribution of care coordinators across practices, and the development of trust not only between coordinators and patients but between coordinators and physicians. For example, care coordinators who divide their time among practices get weekly schedules of when their patients are visiting doctors so that they can plan their schedule to intersect with patients while they are in the waiting room. In accord with Boling's observations, care coordinators also do at least one home visit during their first year in a

new relationship. “There are all kinds of ways to foster relationships, but it is hard, and it is something that requires a conscious strategy and investment.”

## **The Locus of Co-Management**

The most prominent topic in the discussion period concerned, as David Keller from the University of Colorado School of Medicine put it, “Who’s the captain?” Who is piloting co-management and team care so that it is optimized, especially with diverse teams?

Ferris noted that the default answer is the primary care provider, with the care manager as a backup, but there are exceptions, as in the case of severe heart failure, cancer, or transplant patients, who are not managed from the Partners primary care embedded high-risk care management program. He also said that his institution is increasingly writing compacts between primary care physicians and specialists to define this issue. “A compact is a way to get the conversation going.”

Boling observed that the same issue has arisen in geriatrics, where a discussion has been ongoing whether the physician with first call is responsible for everything that might happen with a patient. The financial support needs to go to the person or people doing care coordination case management, he said.

Lail pointed to the importance of empanelment so that both patients and team members know who they are going to see. “When we went to empanelment, we found it to be incredibly valuable.”

Eileen Forlenza of the Colorado Department of Public Health and Environment said that families would like the consistent source of care to be the pilot. “Medical home” should be treated as a verb, she said, so that patients experience a medical home approach no matter what the setting. She also noted that parents often end up as the pilots, especially when providers are unwilling to take on that role.

Carolyn Allshouse from Family Voices of Minnesota said that organizations like hers are providing exceptional support to families throughout the country: helping them navigate complex systems, assisting them with finding insurance, and cobbling budgets together to keep programs afloat. But these services also build competency in families—their feelings of being able and competent in caring for their children and families, according to data collected by her organization. In addition, they have shown a decrease in emergency department visits for families who have participated in the program. Health plans should consider these results in their funding decisions, she said.

Richard Antonelli from Boston Children’s Hospital said that representatives of the child health community group “should be present at every single meeting around accountability, care integration, and financing methodologies.” Ferris agreed that there should be one system of care coordination for high-risk patients, no matter their age.

## Session 6: Costs, Financing, and Payment for Complex Care

The final panel returned to the policy issues discussed by the first panel (see Chapter 2), but with a more specific focus. As facilitator and presenter Suzanne Fields of the University of Maryland put it, the panel looked at “how we’re going to finance for all the things we’ve been discussing.”

### Meeting Needs Through Health Care Reforms

Four trends in the Medicaid program, and in health care more broadly, are having an impact on children with special health care needs, said Catherine Anderson, vice president of state programs at United HealthCare Community & State, which serves more than 5 million Medicaid beneficiaries in 25 states: payment, delivery, the integration of benefits, and the transition to managed care.

Medicaid is a complex program that varies greatly from state to state and from population to population, Anderson observed. It has a variety of funding streams and interacts with other funding streams that pay not only for medical care but also for social supports. It covers a large number of children—39 percent of all U.S. children younger than 18 as of 2014. Of children with special health care needs, about 36 percent were covered by public insurance.

Of children with special health care needs, 21 percent live in families below the federal poverty line, and an additional 21 percent and 29 percent live in families between 100-199 percent and between 200-399 percent of the federal poverty line, respectively. This 71 percent of families having children with special health care needs qualify not just for Medicaid but for a variety of other programs. At the state level, 15.6 percent of state funds went for Medicaid in 2015 (Figure 7-1). Counting all funds expended by states, including federal funds, Medicaid consumes more money than K-12 education, and Medicaid is growing faster than any other program. “I can tell you that states are freaking out” because of these numbers, said Anderson, and “it’s getting worse, because that piece of the pie is growing substantially.”

Despite these expenditures, many children still have unmet needs, as reflected by the number of children on 1915c waivers and waitlisted for those waivers, with allow for long-term care services in home- and community-based settings under Medicaid.

Increased expenditure is one factor causing states to move populations with complex needs from fee-for-service arrangements into managed care, despite the challenges in doing so. “For a long time, we’ve heard states talk about how complicated it’s going to be when all the Baby Boomers come into the system,” said Anderson. But “what’s more complicated is the number of individuals who are becoming eligible for Medicaid because of disabilities. Those numbers are on a percentage basis outpacing the Baby Boomers’ entrance into Medicaid pretty substantially. Many policymakers weren’t as prepared for thinking about that.”

States are taking on health-care-related reforms at unprecedented rates, said Anderson, including accountable care organizations, pay-for-performance plans, bundled payments, health homes, and super-utilizer programs, though the nature of these reforms can differ greatly from state to state. For example, some states have sought to move most of their providers into pay-for-

performance incentive programs, despite the fact that many providers are not necessarily prepared to care for particular populations, according to Anderson. Managed long-term services and supports are also a priority for most state Medicaid agencies, with some making the transition in less than 12 months, in part because of budgetary pressures. Only a few states, often with largely rural populations, still have no Medicaid managed care. “From our perspective, they are some of the most challenging states to think about how do you manage populations—especially complex populations.”

In addition, more states are integrating behavioral and physical health, said Anderson. In specialized contracts, people who have significant behavioral health issues are in a different managed care plan. In other cases, behavioral health is part of the contract.

Anderson discussed some of the considerations United HealthCare Community and State takes into account in running health plans. The majority of its Medicaid beneficiaries are children, including a growing number of children with special health care needs. The organization also runs specialty programs for children with special health care needs in Arizona, Texas, and Michigan. She said that the best approach is to have “a health plan within a health plan” for complex populations. “We cannot very well manage all kids, regardless of their needs, in the same way. By creating a team within a team, we have been more successful in being able to meet the needs of the children we serve.” Much of the work is done on a case-by-case basis, and needs to be, said Anderson. Health plan expertise with complex populations, and especially in leadership roles, is valuable, she said. States (or court orders) often have specific programmatic requirements, timelines, or staffing parameters that must be accounted for in planning and costs, which is one reason why appropriate legal counsel and advisors are critical.

She observed that care is fully integrated, so that a care manager thinks about “physical health, behavioral health, social supports, all of those things together in a single plan of care.” At the same time, the organization is working with providers along a continuum of creating models to improve care. Resources that can contribute range from transformation specialists who can help practices think about integrated care to behavioral health specialists who can be added to a practice but are paid for from a separate financing pool.

From a benefits standpoint, plans need adequate flexibility within the system, Anderson said. However, ensuring rates that allow for this flexibility can be challenging. Not all benefits and services children with special health care needs receive are included in managed care contracting. Sometimes services are anticipated to be provided without proper inclusion in rate setting or without the encounter data available to include in rates. Integrated benefit design limits cost shifting and improves the return on investments in care and comprehensive solutions. Also, EPSDT requirements, guidance from the Centers for Medicare and Medicaid Services, and state definitions for medical necessity all can have significant impacts on the scope of services provided.

Caregivers will go anywhere to get services if they feel services are not adequate where they are located, Anderson observed. Also, expertise for unique conditions or diagnoses is often limited, which requires that families seek services outside of network. “We run a plan... in Hawaii,” said Anderson. “Those kids are on planes a lot. We have to be comfortable with that to make it

work.” Environmental needs and home modifications are a frequent and critical need, which must be considered when thinking about the network.

Rates have to be actuarially sound and financially viable, Anderson observed, and rate methodologies should be transparent and appropriately incentivize the use of home- and community-based services. Rate cell development will be informed by historical claims experience specific to children with special health care needs, the regional characteristics of the delivery system, and the state’s costs for existing case management activity and other expenses. Periodic rate reviews and adjustment may be necessary if rates are not adequate during the first few years of operation.

“There has to be reasonableness in the savings assumptions that are applied,” Anderson said, “not an assumption that you put managed care in and suddenly half of the dollars are going to go away.” Though there may be opportunities to improve outcomes and quality, meeting children’s special health care needs often does not produce significant health care system savings.

United HealthCare Community & State has a set of essential elements that the organization discusses with states in designing programs. First, health plans should be afforded sufficient flexibility to develop dynamic, high-performing networks—defined as optimal quality and value, Anderson said. States should also determine reimbursement during implementation and consider developing incentive models to encourage provider participation in managing care for children with special health care needs. Network adequacy requirements need to reflect the geographic limitations in the state that can affect access to pediatric specialty providers such as pediatric centers of excellence and multidisciplinary teams of pediatric specialty providers. In addition, the state should encourage the use of innovative alternative delivery such as telemedicine and other innovative programs. “There are still many states that do not allow for the active use of telemedicine, which has become a bit of a battle in many states,” said Anderson. “That continues to be a significant barrier for the use of technology to solve some of the access issues.”

Stakeholder engagement needs to occur early, often, and on an ongoing basis, Anderson said. Health plans should be maintaining active member advisory boards that are either a cross section of all the individuals they serve or subset boards that are focused on specific populations.

Finally, health plans do not necessarily understand how to use community-based services well. Program design should encourage innovative collaborations between health plans, providers, and other community-based organizations to improve quality and access and promote the sharing of information across the delivery system, Anderson said. “One of the best things a state and managed care organization can do is to make sure that they know how to put the pieces together and how to leverage what is being done really well in the community.... Invest in those things that are being done really well in the community, so that those programs can grow and provide additional supports to additional children in a meaningful way.”

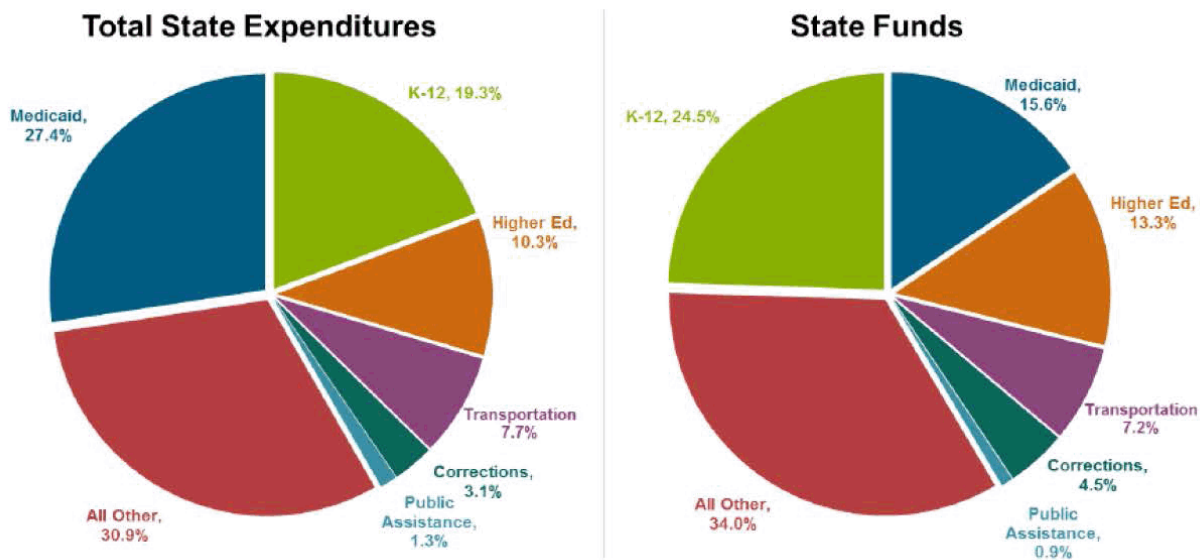


Figure 7-1. Counting all federal and state funds, state expenditures for Medicaid are the largest state expenditure (left), while Medicaid is the fastest growing component of state funding (right). Source: National Association of State Budget Officers Annual Survey

## Moving to Managed Care in Texas

Texas Children's Health Plan in Houston is a pediatric health maintenance organization that is part of Texas Children's Hospital, which is affiliated with Baylor College of Medicine. The health system has 1,200 primary care physicians, 3,000 specialists, and 77 hospitals, while the plan is responsible for about 48 percent of the Medicaid and CHIP population in its 20-county service area. Despite the availability of the health care system's resources, keeping children in a community setting is better for the Texas Children's Health Plan than putting them in the hospital, said the plan's president, Chris Born. Care in the community is the "right place, right care, right time, right cost," he said.

Texas Children's Health Plan has used a common platform for managing its Medicaid and CHIP population, which has made it possible to analyze use and cost. Of approximately 57,000 Medicaid children who were enrolled with no more than one month of lapsed time in the plan, the top 10 percent of children were responsible for 57.2 percent of the health plan's costs. Furthermore, the bottom 90 percent of children, in terms of costs, were fairly consistent in their use of resources, whereas the top decile had much greater variability. Those children would be the focus of a care management program, Born said.

The variability of the most expensive children can lead to rapidly changing financial prospects, Born observed. "The only way that I can make that work is because I have the 52,000 children who aren't consuming as much health care to balance that out."



As of November 1, 2016, children who qualify for Medicaid as a result of a disability are moving into Medicaid managed care delivery systems, Born noted. The Texas Children's Health Plan will be responsible for all medical, behavioral, pharmacy, and long-term support services such as private duty nursing, personal care services, all durable medical equipment, adjunctive services, wheelchairs, and modifications. "It's a whole new scope of services that we'll be providing, but it's going to give us new visibility into how the health care system works."

The estimated revenue premium with a 50 percent market share is \$600 million to \$700 million, compared with an estimated care delivery for all of Texas Children's Hospital of \$1.8 billion. Having such a large portion of revenues capitated will "change transformationally the way that we provide care for this population," said Born. "Everybody's thinking about how we can do things differently to make the lives better for the children we serve."

Many expenses for these children will be for services outside the hospital, such as home care, durable medical equipment, private duty nursing, and personal care. Furthermore, caring for the children in this population costs Children's Texas Hospital millions of dollars each year. As a result, a number of steps will need to be taken, said Born, to care for these children effectively and efficiently. Focusing on the highest cost children, reinsurance, risk adjustments, matching children with physicians who can take care of them, and high-functioning medical management all will be necessary to make the transition. Individualized care plans will be on both a member portal and a provider portal for distribution throughout the system. Behavioral and medical health, community involvement, and family engagement will all be integrated. A new and sophisticated clinic for children with medical complexity is being established.

This population also will be served by new captive medical homes that combine obstetrics, pediatrics, integrated behavioral health, and integrated clinical, pharmacy, vision, dental, and other services. These integrated clinics are "open from 7 to 11, on Saturdays and Sundays," and patient registries use the same electronic medical records system, said Born. The results from these new integrated, patient-centered medical homes have been "phenomenal," he concluded.

## **Financing Wraparound Services**

As Suzanne Fields of the Institute for Innovation and Implementation at the University of Maryland School of Social Work noted, mental health disorders are the costliest health condition of childhood. As such, the financing of behavioral health care offers several important lessons for the financing of care for children with complex health care needs, despite the bifurcated funding system for behavioral health in the United States.

One lesson is that a dozen or so states are now reimbursing, through Medicaid, families with lived experience to serve in professional roles. (Simons and Mahadevan, 2012.) As suggested earlier in the symposium, this innovation could have much more widespread benefits if it were implemented elsewhere.

A relatively small percentage of children with behavioral health needs drives a high percentage of the Medicaid spend, Fields noted. A landmark study conducted by the Center for Health Care Strategies examined Medicaid expenditures for children (Pires et al., 2013) and found several

interesting things. Children in Medicaid using behavioral health care represent fewer than 10 percent of the children enrolled in Medicaid but account for an estimated 38 percent of total Medicaid child expenditures. Their mean expenses are almost five times higher than for Medicaid children in general (and seven and nine times higher, respectively, for children in foster care and for children who are disabled and receive Supplemental Security Income). Furthermore, this represents only children who have paid claims and does not capture children with behavioral health conditions that have not been diagnosed and/or have not resulted in delivery of a service, “so we can anticipate that the need is much greater.”

The study also found that data are even more skewed toward the end of the distribution. Children representing the top 10 percent of behavioral health expense are nearly 18 times more expensive than Medicaid children in general. Their mean expenditures for behavioral health services are more than \$27,000 and for physical health services are more than \$10,000. Compared with all children in Medicaid, whites are more likely to receive behavioral health services and Hispanics are less likely.

Despite the evidence of unmet needs, practices that are supported by evidence generated through randomized controlled trials, such as wraparound services and therapeutic foster care, are underutilized among children in Medicaid who use behavioral health services, Fields said. Most children in the Medicaid program do not have a high-cost chronic medical condition, which again reinforces the opportunities to be gained by focusing on behavioral health.

Without special protections, behavior health dollars tend to get swallowed up or overtaken by physical health needs, Fields observed. Research also has shown that when adult and child behavioral health dollars are integrated, child behavioral health dollars tend to be absorbed by adult services. Behavioral health conditions, except for ADHD, have been associated with difficulties in assessing specialty care through those primary, medical home models (Sheldrick and Perrin, 2010). The question raised by these observations, said Fields, is how to protect behavioral health dollars to provide children with the range of services that they need.

One need is for customized and intensive care coordination approaches for children with significant behavioral health challenges. The majority of these children's needs for coordination are related to other systems and not necessarily to the range of physical and medical health care seen in pediatric populations. The biggest cost drivers for children in Medicaid using behavioral health services are residential treatment and therapeutic group homes and psychotropic medications. Other drivers of Medicaid costs are the use of the emergency department for regular care, the inappropriate use of psychotropic medications, and duplication of services. Strategies exist to deal with each of these drivers of increased costs, Fields noted, and could be much more widely implemented.

Fields described several examples of states that have taken on these problems. For example, a growing number of states have implemented intensive care coordination using a wraparound approach for children with serious behavioral health challenges, which is an evidenced-based practice that includes professional and other supports, including support for housing, education, and welfare or juvenile justice needs (Simons et al., 2014). For example, in Milwaukee County, Wisconsin, the Wraparound Milwaukee Care Management Organization brings together funding

from multiple systems that serve children to create a single pool of dollars to meet children's needs. The benefits to child welfare, juvenile justice, and education generated by this program have been substantial, said Fields. The program also supports the Family Navigators program, which supports families in navigating the system through paid parent partners who work directly with families alongside behavioral health clinicians.

Another example is from New Jersey, which has been blending dollars from across multiple child-serving systems to do intensive care coordination and create a single point of accountability. That state, too, has been investing in the workforce and in centers of excellence to support the training needed across the diverse systems that are involved. Similarly, Georgia has been credentialing adult peer partners, expanding to family partners as to provide professional services through the Medicaid program.

Fields drew several conclusions from these examples. First, the return on investment from spending on children often goes to systems other than health care. Also, more than one payment lever is needed to provide comprehensive service, she said, including a range of financing approaches above fee-for-service as a way of increasing the uptake of new services. Finally, work is being done on risk-adjusted population case rates to create a benefit array that will work for individuals.

## **Financing Needed Services**

The major topic of the discussion session was how to cover the services that children and their families need. For example, Lisa Rossignol of Parents Reaching Out observed that the expansion of Medicaid and other programs has put pressure on sources of support so that some families are losing resources on which they have relied in the past. In some cases, families are even being forced to reinstitutionalize their children and go back to work because they no longer have the resources they need to care for their children. “Practitioners need to understand... how backwards we're going and the lives that we're endangering.”

Anderson agreed and observed that the biggest challenge is how to get paid for needed services that are not now covered, such as greater use of parent respite services. “Without respite, you're going to have an emergency room visit that was unintended and unnecessary,” she said. “Making the investment at the right place at the right time is logical. Unfortunately, it doesn't always fit with how programs are designed.”

Fields added that financing blended or braided with other social support programs can help provide some of these needed services. “It'd be a very interesting discussion to talk about making Medicaid cover respite. We know that's the number one service parents want.”

Elizabeth Priaux of the National Disability Rights Network pointed out that ensuring adherence to the standards established by the EPSDT program (see Chapter 2), in both the Medicaid program and in private insurance programs, would help meet the needs of patient populations with medical complexity. She also made the case that managed care programs need special protections for children with complex care needs, but states are increasingly adopting global waivers that eliminate special carve-out programs. To this observation, Fields responded that

“we see great examples on the carve-out side and we see not-so-great examples on the carve-out side. One of the pieces that we want to do is move away from an either-or discussion and go back to that concept of what are the levers, what are you trying to do for children, and what strengths does your system already have to work with.”

## **Developing the Workforce**

A subject discussed briefly at the symposium was how to develop the workforce that will be needed to provide services for children with medical complexity. As Dennis Kuo of the University of Arkansas for Medical Sciences noted, “having personally been involved with hiring and training of care coordinators, it takes a while to get folks up to speed.” Born observed that the requirements put in place by states require greater investments in training and personnel. Anderson added that some states may have the flexibility to leverage other resources such as providers’ offices or community-based organizations to develop the workforce.

## **Standards for Complex Care**

Finally, Edward Schor of the Lucile Packard Foundation for Children’s Health pointed to the importance of developing a set of standards for complex care clinics that define the range of services and care they provide. By identifying capabilities and justifying adequate reimbursement, establishing such standards “would be a good step toward increasing the sustainability of complex care clinics.”

At the conclusion of the symposium, Schor thanked all of the presenters, facilitators, and other participants, including the staff members who kept the meeting running smoothly. The Foundation is “interested in ideas and proposals to advance this field,” he said. “If you have some ideas for follow-up, continuing this discussion, taking up pieces and moving into other arenas, there's a lot here. We see this as a springboard for other things, and we are open to suggestions from any and all of you.”

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