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Five Keys to Success: Advancing Care Models for Children with Complex Medical Needs

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In the United States, approximately one in 25 children is considered “medically complex,” challenged with multiple, chronic, severe health conditions and requiring substantial medical and psychosocial support. The number of children with complex medical needs is expected to double in the next decade – increasing from three to six million – as advances in medicine and technology reduce mortality rates. These children typically require ongoing care provided by numerous pediatric specialists, many found only in pediatric centers of excellence, as well as access to services and providers found outside the healthcare system. Families often travel long distances for specialized diagnostic and treatment services, and assume much of the responsibility for care coordination and communication among and between providers, without the benefit of a comprehensive care plan. The stress, strain and cost of navigating, managing and coordinating their child’s care within a fragmented health delivery and financing system is a significant part of the total burden of care to the family and the healthcare system.

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The cost of providing care to children with medical complexity is estimated to be as much as 10 times the costs for other children. Approximately two-thirds of these children are covered by Medicaid, and estimates suggest this population accounts for more than 40% of Medicaid's total spending on children. The highest area of medical expense is associated with inpatient care, which accounts for as much as 80% of the total healthcare cost. While only 4% of the total pediatric population, these children represent approximately 10% of admissions to children's hospitals, 25% of patient days and 40% to 50% of hospital charges. The financial impact on families is also significant; a national survey reported that more than half of the families of children with special healthcare needs experience financial hardship or had a family member stop working to care for their child.

As the focal point for care, leading children's hospitals are launching new clinical, operating and care management models designed to support better coordination and delivery of care across the continuum of inpatient, outpatient and community-based services. These models promote engagement and alignment of primary and specialty care physicians, other clinicians, patients and their families around a comprehensive plan of care with clearly defined outcomes and accountabilities that addresses medical and social needs and resource requirements to achieve optimal health status and quality of life. Importantly, they address the full spectrum of patient and family needs, defining the approaches to managing these children from the time they are on-boarded into the program, through transition to adulthood. This paper will explore the power of a comprehensive program for children with medically complex needs, and share the experiences and lessons learned from several leading children's hospitals in designing and implementing these targeted programs to advance the care and support of patients and their families.

The Challenge of Delivering and Managing Care

Patients with multiple acute and chronic illnesses and comorbidities require extraordinary levels of coordination among primary care physicians (PCPs) and specialists, including hospitalists who often manage the inpatient care. Primary care practices are organized to address prevention and wellness and manage acute needs of generally healthy children. Primary care physicians may face challenges with inadequate time and reimbursement for children with greater needs, and most practices do not have sufficient care coordination support to help patients and their families navigate the myriad of specialty care services required. Often, PCPs will quickly refer more complex cases to specialists, where
they consume a large percentage of those physicians’ capacity and challenge their ability to meet the ambulatory and inpatient needs of the broader pediatric population. Children’s hospitals often face challenges managing the emergent medical needs and inpatient care delivery of this population, including ensuring the optimal service assignment, communicating and coordinating care among services, and providing comprehensive post-discharge planning and education. Many hospital and practice-based care coordination services do not have sufficient knowledge of community-based resources that can provide additional support and improve the quality of life for patients and their families.

Often, there is no comprehensive plan of care to provide caregivers with an overall picture of the patients’ full spectrum of health issues, or to support patients and families in health maintenance and anticipation of future healthcare needs. Even when a plan of care is in place, communicating to the numerous care team members and sharing information across practices and inpatient settings can be an enormous challenge. Further, the nature of these patients’ clinical conditions makes care planning complicated and time consuming, and often results in plans of care that can be difficult to understand or navigate. In their desire to better meet the needs of patients, providers will often look to familiar resources to address perceived gaps in care and reduce the burden on patients and their families. At times, this leads to inefficient and unnecessary deployment of high cost resources to address perceived needs. For example, physicians may refer patients to home care services to monitor the patients’ clinical condition or to address basic needs and activities of daily living which could be supported by less expensive technology or community-based resources.

**Children's Hospitals Leading the Way**

Across the country, leading children’s hospitals have developed new specialized programs and approaches to better serve children with complex medical needs and reduce the burden on patients and their families. The success of these programs is founded on greater engagement and alignment of families and interdisciplinary care teams in developing comprehensive plans of care that address current and anticipated future medical needs, as well as the personal and social factors that affect quality of life. Central to these plans is the definition of broad-based clinical and non-clinical outcome goals, including achieving optimal health status while maintaining independence in the least restrictive environment possible. To achieve these goals, programs are designed to support greater integration and collaboration among health, education and other social systems that together enable children with medical complexity to achieve physical well-being, meaningful social interactions, individualized education and training, and optimal quality of life.

Evidence shows that many of these programs have achieved material improvements in both clinical quality and cost through better care planning and coordination as well as more proactive preventive care. A review of 12 leading studies estimated that better care coordination and the creation of specialty medical homes for children with complex medical needs could reduce utilization of inpatient and emergency department use by 40% and 20% respectively. Another recent study compared outcomes for high-risk children with chronic illness who were treated at a comprehensive care clinic at the University of Texas, Houston, to those treated at private offices or faculty-supervised clinics. The study showed a decrease of 55% in the number of children with a serious illness for those treated at the high risk clinic, as compared to "usual care," and a reduction of total hospital and clinic costs from approximately $27,000 to roughly $17,000 per year. Similar results have been achieved at a number of other children's hospitals after the opening of comprehensive care clinics for medically complex kids. Arkansas Children's saw a decrease in the monthly Medicaid costs per patient from approximately $4,700 to a little over $3,500 in just one year following the patient’s first visit to the comprehensive care clinic, driven by reductions in utilization of inpatient and emergency services. At Primary Children’s Medical Center, the comprehensive outpatient program for children with medical and psychosocial...
complexity, fragility and technology dependence delivered improvements in patient and family satisfaction as well as health outcomes and cost: over 85% of parents expressed agreement with the statement, "I receive exactly what I want and need, exactly when and how I want and need it."8

Increasingly, children's hospitals are being asked to demonstrate their ability to improve outcomes, manage clinical variation, and reduce total cost of care for medically complex patients as a critical value proposition to their communities. This value proposition is being put to the test by new narrow networks and ACO products which require children's hospitals to demonstrate differentiating levels of value, or be excluded. Many children's hospitals have approached the management of children with medical complexity as an opportunity to advance their journey to value by focusing on a population with significant opportunity for quality and cost improvement. A number of programs and pilots have been launched in partnership with state Medicaid programs and commercial payors who recognize the opportunity to collaborate with children's hospitals to reduce total cost of care and improve outcomes. As the payment environment continues to shift from fee-for-service to more value-based models, children's hospitals have also found that the experience of managing this population can help build new organizational capacity and capabilities that support broader population health management goals.

New Models for Coordinating and Delivering Care: The Complex Care Team

Leading children's hospitals are developing new models to address the unique clinical and social needs of this population. These models differ in terms of clinical scope and size of the population served, with some designed to manage large populations of Medicaid patients using a broad clinical definition of medical complexity (e.g., using all patients with CRG 5b through 9), and others focused on the most expensive and highest utilizers of services. Some programs exclude patients who are supported by other multi-specialty care management programs, for example transplant and cancer. A few programs include siblings of patients with complex medical needs as a means of providing additional support to families. Despite differences, these programs share a common goal of enhancing support to care teams, patients and families in care planning and delivery, communication and transition management across providers and settings, and access to community-based services.

Most programs have a dedicated Complex Care Team that includes physicians, nurses, case managers, social workers and non-licensed workers who play an active role in non-clinical aspects of care coordination, including liaising with community resources, scheduling appointments and arranging transportation. Some programs include mental health professionals, pharmacists, nutritionists and palliative care specialists. One key difference among programs is the relationship between the Complex Care Team and the patients’ primary care physician or medical home. In some cases, PCPs retain their relationships with their patients, providing a full-range of prevention and wellness services, as well as coordinating specialty and complex care needs. In other cases, the Complex Care Team becomes the medical home, assuming responsibility for comprehensive management of clinical needs across the continuum. Some programs use a hybrid approach. The three different models are illustrated below:
Care Team Model and Care Management Approach

**Consultative Model**
- Patients retain relationship with their primary care physician as the medical home
- The PCP-based medical home provides all essential routine and well-care services and supports the coordination of care for specialty and chronic care needs
- Complex Care Team consults with the PCPs to support care planning, coordinate complex medical needs and support transitions across care settings
- Complex Care Team rounds on patients when admitted to the hospital to support coordination of care and communication among specialists and PCPs

**Medical Home Model**
- Complex Care Team becomes the medical home providing the full range of services including prevention and well-care, and coordination of care for all chronic and complex needs
- Complex Care Team provides care in both the ambulatory and inpatient settings on either a rotational basis or using separate teams
- Complex Care Team works closely with specialists in care planning and coordination
- Patients requiring hospitalization may be admitted to a dedicated complex care unit or a specialty care unit; Complex Care Team rounds on inpatients

**Hybrid Model**
- Some patients retain their primary care physician as their medical home while others utilize the Complex Care Team as their medical home
- Where PCP relationship is retained, Complex Care Team operates as in Consultative Model
- As in the Consultative Model, the Complex Care Team consults with PCPs and specialists to support care planning, and rounds on inpatients
Differences in approach are often driven by the relationship of the children's hospital to the primary care physicians; organizations with a largely independent primary care base typically develop programs with a “consultative model,” while organizations with a largely employed primary care base more often use the “medical home model.” The approach may also reflect the primary care physicians’ capacity and comfort with management of this population. Reimbursement challenges, the need for longer visit times, challenges in care planning and significant care coordination needs with limited resources sometimes results in primary care physicians transitioning the relationship with patients and families to the Complex Care Team.

Regardless of the approach and model selected, programs must carefully define the roles for the primary care physicians and Complex Care Team. Families should understand these roles and have clarity around the point of contact for routine pediatric primary care, urgent and emergent care, and general medical questions related to health maintenance or exacerbation of underlying medical conditions. Families should also understand the role of the Complex Care Team in supporting access to services outside the healthcare system. Particularly in the hybrid model, the Complex Care Team must have clarity around their relationship with each patient, and ensure that they are managing the full continuum of needs of those children for whom they are the medical home, while coordinating with and supporting PCPs for care of the other children.

For hospitals who have or are engaged in developing a clinically integrated network (CIN), the approach used for managing medically complex kids must be aligned with the CIN's clinical operating model and approach to care management. Specifically, the roles and responsibilities of the Complex Care Team should be synergistic with the CIN’s approach to care management, transitions in care management, use of community health workers and social workers as examples. The assignment of accountability as a pediatric medical home for these children has implications for providers’ roles in achieving quality and cost improvement consistent with the general pediatric and specialty measures established by the CIN. Developing consensus among physicians and creating a shared understanding of the requirements for demonstrating value can be complicated with the shift in relationships and accountability inherent in a new model for managing the care for these children.

**Addressing the Full Spectrum of Patient and Family Needs**

Regardless of the model selected, successful care management should be organized to address the full spectrum of patients’ and families’ needs – both medical and non-medical – across the continuum from patient onboarding through the transition to adulthood. Clearly articulated processes will need to be defined for how the program and the Complex Care Team will engage with patients, families and caregivers, and support the connection to services outside the health system. While many programs begin with a focus on better coordination of medical needs and clinical care, more mature programs have recognized the importance of supporting families in connecting with social services, school systems, financial resources, legal resources and other community-based services. This holistic view that extends beyond clinical measures to include improvements to quality of life and reduced burden of care is a hallmark of high-performing programs.

*Regardless of the model selected, successful care management should be organized to address the full spectrum of patients’ and families’ needs – both medical and non-medical – across the continuum from patient onboarding through the transition to adulthood.*
A framework for developing the core components of an effective care management model for children with complex medical needs is illustrated and described below:

For children’s hospitals considering developing a program, key elements include:

- **Aligning around Program Goals and Scope of Service:** Patients and families of children with complex medical needs have goals that extend beyond narrow clinical outcomes; while they are looking to achieve optimal health, they also have aspirations for independence and a meaningful family and community life. Organizations will need to align around a comprehensive set of goals and expectations for performance that include clinical outcomes, utilization, cost of receiving and providing care, quality of life, burden of care on families, provider satisfaction and other measures. There must be clarity around program scope and size, and well-defined clinical criteria for patient eligibility (e.g., three or more chronic conditions, three or more inpatient admissions or ED visits within the past 12 months), as well as a process to assist those patients who do not meet criteria for the program. In addition, there will need to be a process for patient recruitment and referral management, and communication to primary care physicians, specialists and case managers regarding the program, goals and
eligibility. Some programs have also involved payors in the identification of high cost, high utilization target populations.

- **Patient and Family On-Boarding and Care Plan Development.** As patients and families are referred into the program, a critical initial area of focus is the development of a comprehensive plan of care. Active engagement of patients and their families in defining outcomes, along with input from the entire care team, is essential. The plan should support the patient, family and care team in understanding the requirements for maintaining optimal health status and in anticipating and addressing potential future healthcare needs. Care planning may include a visit to the patient's home to understand the environment and support the family in interacting and connecting with their child on a daily basis, and to identify ways to maximize the child's ability to maintain independence. The plan of care should also define the critical points of access to services outside the health system including the school system and other social and community-based services. Front-end financial counseling is an important element as there may be resources available to families to help offset the significant financial burden of an intensive healthcare regimen that may include physician, hospital, home health, technology, pharmaceuticals, therapy and other care.

- **Care Delivery and Transition Management:** The care management model should define how the Complex Care Team will support patients and their families in achieving optimum health status and in accessing care and interacting with caregivers in all settings. In addition, the model should actively facilitate engagement, coordination and communication among providers and across settings.

  - **Self-care, Primary Care and Other Outpatient Care:** For patients and their families, the primary objective is to stay as healthy as possible and minimize the need for hospitalization or other interventions. As such, programs must address a continuum of care that includes self-care, primary and preventive care, specialty care and urgent/emergent care. Program design should include the processes for providing support to primary care physicians including care management; provider, patient and family education; and deployment of clinical protocols and checklists for specific elements of care. Since many patients are seen by three or more specialists, there should be well-defined processes for coordinating specialty care needs and sharing information among specialists to promote seamless care. There should be a clear process for responding to urgent and emergent situations, including a protocol for directing patients and families to the appropriate care setting. Patients and families will need to understand the support that can be provided by the Complex Care Team such as education on managing basic medical needs like nutrition, respiratory care, medication management, mobility and pain. There may also be opportunities for use of technology to support patients, families and caregivers in identifying and addressing health risks to prevent avoidable hospitalization or emergency care.

  - **Inpatient Care:** For most children's hospitals, inpatient care delivery represents both an area of considerable strength and an opportunity for improvement. The clinical management of inpatient episodes of care is often led by clinicians who are among the best in their field. However, there is less consistency in processes for determining the optimal service assignment (e.g., hospitalist vs. specialty service), as well as challenges with communication and coordination among the care team including attendings, consulting physicians and advanced practice providers. Additional support for physicians may be needed for on-call and after-hours coverage, and there are often gaps in discharge planning and management of post-acute transitions. Program design should define the role of the Complex Care Team in the management of inpatient care, either as the attending team or as a consult service to support care planning and delivery. The Complex Care Team can also be an invaluable support to discharge planning as they should have extensive
knowledge of the patient, family, available resources and community services. The team can also support communication to primary care physicians and post-discharge follow-up with specialists as needed.

- **Integration with Services outside the Health System.** A key feature of more comprehensive programs is the support provided to patients and families in accessing services that are outside the health system and essential to promoting independence, optimizing social interactions, achieving maximum independence, and transitioning to adulthood. Families often benefit from support groups for parents and siblings, and assistance with health insurance or obtaining additional financial support through grants and waiver programs. Program design should include processes and resources focused on creating awareness of, and access to, developmental and early intervention programs, educational services, recreational opportunities, specialized vacation camps, and other community-based services. Parents may also benefit from help in advocating for their children, for example in the creation of an Individualized Education Program (IEP) that defines the child’s learning needs, the services the school will provide and how progress will be measured.

- **Transition to Adulthood:** As patients transition to adulthood, they may face physical and cognitive barriers, and families often lack the information needed to navigate the transition successfully. For hospitals, the transition from pediatric to adult care can have considerable challenges, including activation of patients in understanding and assuming responsibility for self-care and finding adult providers who are comfortable managing their care. Some programs have no upper age limit, allowing the patients’ pediatric primary care physicians and the Complex Care Team to continue managing their care through adulthood. Others begin transition planning several years prior to patients reaching adulthood. Some programs offer a team of transition-care providers who are available 24/7 for consultation to adult providers. Program design should carefully consider alternative models, including the implications on program size and capacity, if ongoing clinical management is retained into adulthood. Further, it is important that the transition model addresses support for important enablers of adult independence and quality of life including higher education, employment, home life, and social interaction.

**Key Requirements for Success**

A well-organized and thoughtfully implemented program can have a material impact on health outcomes, quality of life and total cost of care. In our experience, there are five key requirements for success:

1. **Leadership alignment around the goals for the program and the requirements for success.** While the opportunity for reducing utilization and cost of care may be significant, program design should place primary emphasis on addressing the comprehensive needs of patients and their families, with a clear commitment to improving care delivery, outcomes and quality of life. Doing so will require addressing services within and outside the health system. Agreement on program scope and the size of the population to be enrolled is critical. Many leading programs have started small, focusing on the highest-cost cohort within the population and explicit caps on membership. Other programs have focused on broader populations, e.g., Medicaid patients, with explicit goals for cost reduction and shared savings arrangements. Leadership must be aligned around the vision for the hospital’s and its physicians’ role in the management of this population, and how that role relates to primary care and specialty physicians. Finally, there should be a shared understanding of the degree to which the hospital will assume accountability and risk for the delivery of value, including total cost of care. For hospitals and physicians who are part of a CIN, program design should support alignment with strategic objectives, performance requirements and accountability for outcomes.
2. **Agreement on specific, measurable performance requirements for the program that support the quantification of value to patients, providers and payors.** Expectations should be defined for improvement across multiple dimensions of performance including clinical quality, patient and family experience, provider satisfaction, utilization and cost. Providers must have an understanding of the current baseline, and agreement around the required future performance. If payors participate in the program, or if the program receives other external funding (e.g., grants), there may be explicit performance targets established jointly with funding partners. Programs must be able to assess current and improved performance related to clinical variation, development and implementation of consensus-based standards of care, avoidance of redundant and unhelpful care, and the resultant impact on total cost of care. The value proposition to children, families, employers, communities, and payors must be demonstrable improvements in clinical outcomes, quality of life, patient and family satisfaction and total medical expense. Building programs with these value propositions tangibly in place can facilitate migration to different payment models and collaboration across payment sources to help address funding requirements.

3. **Active engagement of payors as partners.** Many successful programs have been pursued in partnership with Medicaid and/or commercial insurers who have helped fund program investment and implemented shared savings programs to reward providers for management of total cost of care. In some cases, payors have also participated in establishing guidelines for enrollment and recruiting the target population. Engaging payors at the outset is an important strategy for success, and may require risk-sharing by providers and hospitals. Absent payor involvement, some hospitals in markets where there is considerable fee-for-service volume have found the economics of these programs to be challenging or infeasible, as significant investment in staffing and other resources (e.g., space, information technology) combined with a reduction in utilization of hospital services has resulted in a negative impact on overall financial performance. Still, other organizations that have waited to approach payors until after programs have been launched have found it difficult to generate interest from the payors who are less likely to reward performance that has already been achieved. Ultimately, the successful migration toward value depends on the hospitals’ and providers’ ability to demonstrate differentiated quality and cost to payors and employers. Superior performance will also strengthen the hospitals’ and providers’ position to participate in narrow networks and ACOs.

4. **Adequate support to the Complex Care Team.** Providing and coordinating care for these patients is challenging, and organizations must carefully consider how support requirements differ from what is required to support general primary care and specialty practices. Recruiting physicians and other clinicians who are passionate about this population is essential. Training for primary care physicians, patients and their families can reduce the demand on the Complex Care Team and lead to improved outcomes through more timely preventive health and greater awareness of potential medical issues. Supplementing the core Complex Care Team with additional support such as pharmacy, social work and behavioral health professionals should be considered. In addition, it is important to understand the Complex Care Team's capacity and determine reasonable inpatient and clinic caseloads to avoid overburdening the team.

5. **A roadmap and migration plan that is aligned with organizational capacity and permits sufficient time for successful program implementation.** Building a comprehensive program is a significant undertaking and must be implemented in a manner that supports the development of internal capacity and new competencies required to manage the population. There must be time allocated for collaboration with both independent and employed physicians on development of new inpatient and outpatient care models, detailed design of operating models and tools, infrastructure build, and recruitment of leadership and key personnel. The roadmap must also reflect
the time requirements for patient enrollment and the development of personalized plans of care, which can vary significantly based on the size and scope of the program. Particularly if the program is approached as a pilot (e.g., in collaboration with a payor), there will also need to be structured milestones and points at which results can be measured and decisions made about ongoing collaboration or the need for program changes.

**Meeting the Challenge**

A comprehensive program for children with complex medical needs offers the promise of enabling these children to achieve their aspirations for health, quality of life and independence – and can greatly reduce the burden on patients and their families. Designing and launching these programs requires new, innovative models of care delivery and unprecedented levels of integration and coordination of health and community services that challenge the current organization and roles of children's hospitals and pediatric physicians. Programs will need to achieve better quality and lower costs, and hospitals should look to secure funding from payors, grants or philanthropy to offset investments or potential reductions in fee-for-service revenue. When successful, these programs present an opportunity for children's hospitals to demonstrate value and strengthen their position to successfully compete and maintain financial viability under new reimbursement models. Importantly, these programs support children's hospitals in fulfilling their mission and commitment to improving the health and well-being of the pediatric population by closing the gap in care faced by the pediatric population with the most complex medical conditions.

(Endnotes)

2 “Optimizing Care for Children with Medical Complexity.” Children's Hospital Association. 2012
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