Medicaid Reform
For Children

Ideas for Sustainable Reform in Post-Acute Inpatient and Home Care for Children with Special Healthcare Needs in New York

Submitted by

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Introduction

St. Mary’s Healthcare System for Children takes great pride in its singular, integrated approach and commitment to providing a wide array of services for children with special healthcare needs (CSHCN) and in particular, medically fragile children, which encompasses a unique continuum of care including inpatient care, center-based and home and community-based post-acute care. Our goal is to facilitate the transition of children to the least restrictive environment where optimal care can be provided. As a national leader and NY State’s largest provider of pediatric long-term care serving 4,000 children each day, we pride ourselves on understanding the changing needs of our constituents and the changing demands our institution faces to meet these needs.

While licensed as a Skilled Nursing Facility (SNF), St. Mary’s Hospital for Children (97-beds) serves a population with a patient acuity that more closely resembles that of an acute children’s hospital as opposed to a geriatric SNF. **At St. Mary’s, 95 percent of our patients are admitted directly from a Neonatal Intensive Care Unit (NICU) or Pediatric Intensive Care Unit (PICU), necessitating highly skilled pediatric clinicians to tend to high acuity patients.** The majority of St. Mary’s inpatient admissions come from Morgan Stanley Children’s Hospital of New York-Presbyterian, The Children’s Hospital at Montefiore, Cohen Children’s Medical Center of New York, and New York-Presbyterian Hospital/Weill Cornell Medical Center, all of which have an aggregated average length of stay of 5 days. Morgan Stanley, which has the highest case mix index of any pediatric program in the country, admits the most cases to St. Mary’s. (NY State SPARCS, 2006). Length of stay at St. Mary’s averages 3-5 months, during which time the child and his/her family receive a full complement of intensive rehabilitation, habilitation, and medical services until they are discharged home and followed by St. Mary’s home and community programs. The integrated continuum of care provides a cost-effective, family-centered delivery model.

The intent of this paper is to present a clear understanding of pediatric post-acute care and the impact the emerging population of medically fragile children, most of whom are dependent upon Medicaid, will have on New York’s healthcare system and suggest solutions to mitigate the impact to the State while continuing to provide high quality, long-term care.
Cshcn: an emerging population

One in five children in the US has some type of special healthcare need, a ratio that equates to 800,000 children in NY State alone with 76.1% residing in urban cores. (2007 National Survey of Children’s Health Data; 2005/2006 National Survey of Children with Special Health Care Needs).

Healthcare organizations now witness a tremendous increase in the survival of children who have experienced catastrophic illness, severe injury, or complications of premature birth. In medical literature, children with special healthcare needs are those “who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that normally and routinely required by children.” (Westbrook, Archives Pediatric Adolescent Med 2004).

This unique and growing population of medically fragile children presents very real challenges for today’s healthcare system. Providing long-term care for children and adolescents with complex medical conditions is a complicated exercise in medical care management—in quality of care, cost effectiveness, in reimbursement and in issues that deeply affect thoughtful integrated care delivery – service coordination, transition planning, and right sizing of beds, to name a few.
Challenges For Pediatric Post-Acute Care

Categorized along with geriatric nursing homes as Skilled Nursing Facilities, yet caring for high acuity children, pediatric post-acute organizations are the square peg in the round hole of healthcare.

Reimbursement & Regulations
The current structure of reimbursement for pediatric nursing homes has not been able to keep up with the rising costs of care, particularly as the levels of service and patient acuity increase. The State, in its recognition of the importance of these services, has been forced to make accommodations almost on an annual basis to help the 3-4 pediatric post-acute facilities that provide the majority of inpatient care for medically complex children.

The uniqueness of this population is clear, yet the regulations that guide reimbursement and standards of care for medically complex children receiving post-acute care are the same as those for the geriatric population. History has shown that this model results in inadequate reimbursement for both inpatient and community-based pediatric post-acute care, but data would suggest that this model of care is cost effective and ultimately, can decrease expenditures.

Estimated cost of care:
- Acute care facility: $2500-3000 per day
- Pediatric post-acute setting: $750-900 per day
- Pediatric home care setting: $250-300 per day

Nearly 86% of St. Mary’s reimbursement is from Medicaid with at least 50% of St. Mary’s patients representing underserved groups, including low income, minority children. (SMHCS Quality Data 2010). St. Mary’s serves as a safety net for New York’s underserved children, and despite an ever increasing acuity among our patient population, St. Mary’s continues to provide high quality care and achieve strong clinical outcomes.

Long-term care in SNFs for the medically complex pediatric population presents completely different challenges from care for the frail-elderly populations of nursing homes.
Medical complexity and intense care/cost pressures involved in inpatient care delivery at St. Mary’s Hospital for Children are indicated in the following data:

- 95% of patients are admitted directly from the PICU or NICU
- 100% of our children receive at least 1 rehabilitative therapy (PT/OT/SLP); 58% receive at least 2 therapies; 60% receive restorative medical model speech therapy, with goals of care directed towards feeding and swallowing conditions, sensory aversions, and airway management.
- 224% increase in intravenous nutrition (Total Parenteral Nutrition) patient line days from 2006
- 80% of patients receive assistive/supplemental feedings via feeding tubes
- 63% of our patients receive palliative care services; 55% of these patients are under the age of 5. Palliative care encompasses levels of pain management along with medical, psychosocial, and spiritual care, and can be used along with curative measures for children with life-limiting conditions.
- 50% reduction in hospital acquired infections since 2006, despite our increases in patient acuity
- 51% of our patients require monitoring with pulse oximetry equipment to ensure their respiratory safety.
- 37% of patients receive aggressive pulmonary toileting via ABI Vest
- 33% of patients have tracheotomies requiring O2, humidification, frequent suctioning and nebulizer treatments
- 13% of patients receive expert burn and wound care

Despite the increases in patient acuity, St. Mary’s has realized a 66 percent reduction of transfer to acute care facilities (ER) within 30 days of admission for the past 5 years, attesting both to the quality and cost-effectiveness of care.

In the pediatric home care arena, the lowest cost care delivery setting, current Medicaid reimbursement is out of synch with the cost requirements and administrative processes necessary to operate and deliver quality services at home. The current system is fraught with inefficiencies, including a cumbersome enrollment process, costly administrative redundancies, and a fragmented approach to services that leaves parents, as well as many providers, confused as to which program is most appropriate for the child’s needs.

We recognize NY State is pursuing ideas for the modification of this system, and we support the rational reform of Medicaid that does not leave the State’s most vulnerable children behind, and welcome the opportunity to provide expert testimony to the Medicaid Redesign Team.
Emerging Populations

Within the emerging population of children with special healthcare needs are three subsets of children who will have a pronounced effect on the State's healthcare system:

Barriers to Discharge

St. Mary’s has studied nearly 700 inpatients to identify barriers to discharge and to evaluate the etiology of increased length of stay. (Coletti, “Barriers to Discharge in Pediatric Sub-Acute Care,” presented to NYSDOH, 2006). While there are a variety of medical and social issues that are barriers to discharge, we identified that caregiver/parent issues were among the primary reasons, including the risk of abuse and neglect, parents’ inability to plan, guardianship and housing issues. Often the most appropriate solution is foster care and possible adoption. New York’s current Foster Care System is not capable of managing a large number of very complex, medically fragile children. In addition, a significant percentage of children currently in the foster care system have some form of disability or medical fragility. Data from a study of foster care children revealed that 80% of children in foster care have at least one chronic medical condition, and 25% have three or more chronic problems. (McCarthy, 2000). Thus, without improvement or the establishment of a robust Medical Foster Care System, medically fragile children will continue to remain in inpatient settings. For example, at St. Mary’s Hospital for Children, a significant number of our current inpatients are ready for discharge, but lack the appropriate familial and housing supports to accommodate their transition to the community. These children are prime candidates to receive less costly home care services, but remain at St. Mary’s Hospital for Children due to the lack of medical foster homes.

Additional barriers come in the form of parents who are able but unwilling to take their children home from pediatric post-acute facilities and transition to community-based programs and services. This scenario stagnates throughput across the continuum and drives up the cost of care. While we are not suggesting children be forced into foster care, laws may be necessary that allow the State to dictate appropriate placement if parents refuse to take their children home once ready for discharge.

Another barrier to discharge is the lack of adequate reimbursement/approval for home nursing care. In many cases parents who are eager to have their medically complex child return home, find it an impossible challenge to access appropriate nursing care. As it stands now, the system actually discourages discharges from post-acute inpatient facilities when skilled nursing is involved. For example, an infant with short bowel syndrome, who has been hospitalized in a pediatric post-acute inpatient setting for several months, is ready for discharge. However, the parents both work and the child requires 8-10 hours of nursing each day that Medicaid will not approve. So the child remains removed from his family in the more costly inpatient setting at approximately $800 per day, significantly more than the cost to care for him at home.
“Aging Out” Adolescents

Through the advances in medical care and technology, children with special healthcare needs are now living longer than ever and are beginning to age out of their current level of services. These medically complex adolescents and young adults will require ongoing, age-appropriate services, yet their care is relegated to geriatric nursing homes or to a decreased level of home based services. As the children begin to age, so too, do their parents; many of whom are no longer physically capable of caring for their adult-sized children and are concerned for their future. While limited state-wide and national data currently exist, St. Mary’s estimates hundreds of these patients/scenarios will emerge over the next five years. Initial research conducted by St. Mary’s in conjunction with the American Academy of Pediatrics identified more than 300 children within St. Mary’s own patient population who will age out of pediatric programs during this time frame and will require ongoing specialized care. (AAP CATCH Grant, 2008).

Currently there are 15,000 medically complex children in long-term care facilities or outpatient home care programs in NY State who will eventually “age-out” of pediatric programs. (2006 NY State SPARCS). Ironically, the innovations and advances in medicine that have successfully extended survival and various types of assisted functioning for children have surpassed the progress of the supportive interventions and services required to care for this population.

While New York State is overall trying to “right-size” the number of Nursing Home beds, DOH cites a statewide need of 7,426 additional Residential Health Care Facility (RHCF) beds by 2016, with the greatest area of need concentrated in New York City and Long Island. (NYS DOH; Estimates of RHCF Bed Need by County, March 2010). The number of traditional nursing home residents under 21 years of age in New York in 2007 was 500, and in 2008 – 559, an increase of nearly 11% in one year (NYAHSA, 2010). A steady 10-11% increase of bed-need over 6 years (to 2016) for this “aging-out” population will require an increase of an additional 369 beds in New York’s specially designated units (SNFs or RHCFS).

Out-of-State Dependence

In addition, there are 470 New York State patients who reside in out-of-state SNFs, a significant number of whom are ventilator dependent. (NYS DOH RFP0508311002 Questions and Answers, Out-of-State Medicaid Placements and Special Population Initiatives, 2006). We estimate 40 to 50 ventilator dependent children are currently housed out of state due to the lack of long-term pediatric ventilator beds in New York. St. Mary’s estimates that eight to ten new pediatric ventilator dependent children will emerge each year in the New York Metropolitan Area.
St. Mary’s Integrated Model of Care

St. Mary’s Healthcare System provides a continuum of care for the patient throughout his/her life – from birth to adulthood. St. Mary’s is the largest provider of pediatric long-term care in the State and a national leader and pioneer in complex medical care delivery, with the nation’s first Pediatric Palliative Care Program – the prototype for many other programs nationally; New York’s first Pediatric Traumatic Brain Injury and Coma Recovery Program; the first and largest Pediatric AIDS Home Care Program in New York; and one of only nine multidisciplinary Pediatric Feeding Disorders Programs in the nation.

**St. Mary’s Programs**

- St. Mary’s Hospital for Children – inpatient care
- Certified Home Health Agency
- Licensed Home Care Services Agency
- Long-Term Home Health Care Program
- HIV/AIDS Home Care Programs
- Case Management Programs
  - Care at Home Program (Katie Beckett waiver)
  - Medicaid Service Coordination
- Pediatric Day Healthcare Program for Children and Young Adults (Medical Day Care)
- Early Intervention and CPSE – center-based, home, preschool
- Center for Pediatric Feeding Disorders
- St. Mary’s Kids at Roslyn - Outpatient Rehabilitation
- Durable Medical Equipment

**Specialized Services**

- Pediatric Nursing
- Rehabilitation: Physical Therapy, Occupational Therapy, Speech Therapy
- Respiratory Therapy
- Palliative Care
- Social Work
- Pastoral Care
- Education
- Complementary Care
- Therapeutic Recreation
- Respite Care
- Nutrition
- Behavioral Health/Psychology
- Traumatic Brain Injury & Coma Recovery
- Private Duty Nursing
- Home Health Aide / Personal Care Assistant
The Integrated Care Model: Inpatient Care
St. Mary’s Post-Acute Continuum of Care Model, or “after care,” constitutes high quality care in the least restrictive environment, whether it be the inpatient facility, the home, or the community – care that is cost-efficient, improves quality of life for children and families, and helps maintain the family unit.

The first pillar of care—the anchor—in St. Mary’s integrated care system is St. Mary’s Hospital for Children, an inpatient facility licensed as a Skilled Nursing Facility, though it is difficult to distinguish much difference between the patient acuity seen here and in the area’s acute care children’s hospitals.

Acute care hospitals are themselves facing a critical juncture due to a focus on tertiary care, the high cost of that care, the pressures to decrease length of stay, and the vital need for throughput to an institution like St. Mary’s, which is a vital link, a foundation, in the clinical pathway of caring for medically complex children.

The Integrated Care Model: From Hospital for Home
In New York State there are few programs that provide long-term healthcare to medically fragile children – in their homes, with their families – as a way to avoid the more costly, long-term stays both in pediatric nursing facilities and in acute care hospitals. The largest and most established, and soon the only facility of its kind in New York City, is operated by St. Mary’s Healthcare System for Children.

This program improves the quality of life for children and their families and saves the State significant medical costs – and should be carefully considered if they are included in the Governor’s proposed Medicaid cuts.
Recommended Reform Strategies

The intent of this paper is to present a clear understanding of pediatric post-acute care and the impact the emerging population of medically fragile children, most of whom are dependent upon Medicaid, will have on New York’s healthcare system and recommend reform to mitigate the impact to the State while providing high quality long-term care.

1. St. Mary’s recognizes the State’s need to rein in costs, and we support the rational reform of Medicaid that does not leave the State’s most vulnerable children behind. We offer both short- and long-term recommendations to assist in the reform process.

1.1. St. Mary’s Post-Acute Continuum of Care provides a cost-effective care delivery method for New York’s medically complex children. It is estimated that exempting St. Mary’s Healthcare System and other pediatric facilities and home care providers from Medicaid reductions will have a positive long-term impact, by continuing to provide care to a growing number of children in the least costly care settings.

If the programs cannot remain viable due to reductions in Medicaid, this will have the counter-productive budgetary effect of increasing Medicaid expenditures by prolonging children’s stays in the more expensive acute inpatient settings and failing to provide medical care throughput for those patients who can be appropriately placed in St. Mary’s SNF—where improved health outcomes, the prevention of continued inpatient acuity, and the long-term consequences of poorly managed co-morbidities outweigh the associated costs—or in St. Mary’s home and community settings. Additional costs will be seen by an increase in emergency room and acute care hospital admissions – costs that have traditionally been curtailed by the availability of post-acute pediatric services.

1.2. Children are not small adults, yet the regulations that guide reimbursement and standards of care for medically complex children receiving post-acute care are the same as those for the geriatric population. St. Mary’s recommends the State develop a system of reimbursement and regulatory standards specific to pediatric post-acute inpatient and home care services that will ensure high quality, sustainable care for the future.

1.3. St. Mary’s supports the development of a streamlined, centralized point of entry for patients who require home care services. An individualized assessment tool, similar to Medicare’s OASIS yet specific to the pediatric population, is critical to establish clinical needs and identify the most appropriate care options for the patient. This approach offers the two-fold benefits of reducing administrative inefficiencies as well as providing a more effective method to assist families in selecting the most appropriate Medicaid and Medicaid waivered programs for their children. This is particularly crucial in identifying and addressing the needs of the growing number of medically complex children.
1.4. Over the last 10-15 years, the state has embarked on forms of Managed Care for the geriatric long-term care population including Managed Long-Term Care plans and PACE programs. While these programs appear to be successful in containing costs in the populations they serve, they have not been evaluated in the pediatric population. St. Mary’s has been studying the viability of managed models of care, but the lack of adequate resources and data to appropriately analyze care delivery modalities in this unique population has hindered the development of a model.

We recommend that the State support the studies necessary to develop a possible Pediatric Managed Care model and demonstration project. We believe that any movement of children into these forms of care prematurely without adequate study and review may actually result in decreased quality of care and ultimately increased costs.

2. As the State redesigns the Medicaid system, it is critical to recognize that the pediatric landscape today is significantly different than just a decade ago. Advances in medicine and technology are enabling children to survive illness and injury that were previously unimaginable. New programs must be created, and current ones enhanced, to care for the emerging population of medically fragile children with complex needs.

2.1. It is essential for the State to develop a robust Medical Foster Care Program for high acuity, complex needs children. St. Mary’s recommends linking healthcare providers and foster care agencies or facilitating certain pediatric healthcare providers to become foster care agencies. A modified inclusive care program developed primarily for complex, medically fragile foster children (funded in some part by foster care dollars) would dramatically improve our ability to move children into the community and ease this significant barrier to discharge. This program could also be an option for a select group of non-foster care children with special healthcare needs.

2.2. To address the “aging-out” phenomenon, St. Mary’s is proposing a unique system of alternative residential care for high acuity medically fragile adolescents and young adults. The model of care will maintain this population in a non-institutional setting, and it will provide lifelong services for these young adults who are neither appropriate for a pediatric inpatient nor a geriatric skilled nursing facility. It is our expectation that patients will come from among existing pediatric nursing home residents and those at home whose parent/caregiver are unable to continue to care for them or who have aged out of pediatric services.

2.3. Because of the large number of existing ventilator dependent children and the burgeoning number of children that we will see in the very near future, we believe that an efficient (both cost and time) solution is necessary. Building new facilities to accommodate
these children will be costly and time consuming. St. Mary’s proposes that the State use existing skilled nursing facility space to develop small (20 bed) pediatric ventilator units in existing facilities. We have developed a pediatric-focused care model for this approach that will address all the comprehensive needs of this population. These residences will have the look and feel of a child-friendly, family-centered environment yet benefit from efficiencies inherent in operating within an existing infrastructure. This model would allow for the repatriation of the out of state children in a timely fashion.

2.4. To facilitate care in the most cost-effective care delivery setting – at home – it is critical that the State increase the availability and reimbursement for home care nursing. Home care efficiencies can be achieved by streamlining the approval process with local gatekeepers of pediatric waivered programs, which currently can take upwards of six months, to stimulate throughput from hospital to home. Additionally, the adoption of a pediatric clinical assessment tool will expedite the continuum of services by identifying needs and appropriate programs, which cuts down on redundancy of administrative efforts and offers a clinical road map to parents of medically complex children.

2.5. St. Mary’s recommends that the age limit for pediatric waivered programs should be increased to 21 years of age. This will allow increased time for families to transition their children and match the time when school based services are also ending.

Conclusion

Through our decades of knowledge, experience, and best practices, we are confident that the integrated, skilled inpatient and community-based, home care model we practice, coupled with the recommended reform strategies, can significantly scale down these rising costs and also create higher quality care and living. With appropriate Medicaid funding, St. Mary’s will continue to lessen the dependence on acute care beds, transition children out of SNF beds into the community or home, and at the same time enhance the quality of medical care and life for our patients.