

A Perspective on Cost Effectiveness in Pediatric Comprehensive Complex Care Service Models

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Introduction

As comprehensive service delivery models are being developed to improve care for children with medical complexity (CMC), especially the growing population of the most fragile, financially supporting and sustaining the necessary additional resources their care requires is an almost universal problem. This brief presents evidence on the cost effectiveness of these models and describes the unique challenges in cost effectiveness evaluations for this population. It also points to Medicaid policy opportunities that provide financial support for a developmental period, whether focused on model development or systems building expansion. This information is offered as a resource to help make the financial case for further development and expansion of service delivery models for CMC, with the hope that it will ultimately result in a more cost effective and efficient system of care for this vulnerable population, resulting in better health outcomes.

Background

With U.S. per capita healthcare costs very high and still increasing at a rate above economic growth, financial impact occupies a disproportionate weight in decisions to restructure health care delivery systems, even when the care experience and outcomes show positive improvement. Champions of comprehensive complex care services for CMC must address costs when advocating for their models of care. Public and private health insurers consistently question the value of paying rates that fully support the costs of these models of care, and typically require evidence that these models can yield cost savings from reductions in utilization elsewhere.

Challenges:

The current environment is problematic from at least five perspectives:

1. Evidence for Cost-Effectiveness
While there is considerable cost effectiveness evidence for pediatric comprehensive complex care clinics and programs, it rests on a number of studies of varying CMC cohorts and service delivery responses. However, when reviewed and consolidated, this evidence highlights consistent patterns of improved outcomes and more cost-effective utilization.
2. Challenges in Demonstrating Cost Effectiveness
There are unique challenges posed by this population in developing convincing cost effectiveness evidence for a particular service model. This begins with issues that emanate from the nature of the population, varying definitions, small numbers, heterogeneity (exacerbating the small n) and difficulty in finding a truly mirroring control group for comparison. These challenges extend to consistent biases in healthcare cost effectiveness evaluation, the typical very short time frame to see “results”, and the

narrow focus on healthcare outcomes and costs to the exclusion of other human services and governmental benefits and costs.

3. Federal Financing Opportunities

Federal subsidies, in the form of enhanced matching rates, are available to state Medicaid programs for the teams that usually are the core of pediatric comprehensive complex care service models through the health home provision in the Affordable Care Act (Section 2703) and the ACE Kids Act. Accessing these funds first requires gaining the attention and resource commitment from state policymakers. The relatively small numbers of CMC in any state's Medicaid program and the limited-service models makes obtaining these funds a challenge.

4. Nature of the CMC Population Impacting Service Delivery Models

As a small and heterogenous population, it is a challenge to develop comprehensive service delivery models with accepted standards of functions and resources. For starters, CMC lack a settled standard definition. Definitions are alternatively based on frequency of medical service use, the number of subspecialists involved in a child's care, the number of body systems affected, and sometimes the specific diagnosis assigned to a child. In addition, the design and staff composition of service delivery models will vary depending on the child's medical needs, the family's geographic location, access to medical services, and social circumstances.

This variation is challenging for insurers and agencies because, unlike complex care for older adults, no clear standard pediatric comprehensive complex care model is available for adoption. Various pediatric complex care models have emerged at academic and other specialty centers. These reflect the population served, the perspective of clinician and other healthcare champions, the broader healthcare environment, and the institution's available staffing and resources.

5. The Human Factor

Society views the day-to-day care of CMC, including their health care, very differently than that of adults with disabilities and elders. The presumption is that families will care for their children, no matter how profound the impact and burden of care. In contrast, adult children are not equivalently expected to set aside their lives to care for their disabled or frail parents. In fact, substantial social resources, such as Social Security and long-term care services, have been developed in response to unmet needs of older citizens. Our cost effectiveness lens needs to be adjusted to account for the financial, personal, and social costs incurred by the families of CMC.

Discussion:

Cost Effectiveness and Financing:

There is growing evidence that pediatric comprehensive complex care service models are cost effective. The Center for Medicare and Medicaid Innovation (CMMI) funded CARE Award project, a controlled study, is the most substantial. It showed cost savings as a result of healthcare utilization shifts for 4,530 CMC enrolled across 10 children's hospital complex care programs. The savings highlights were a 4.6% decrease in the total per member per year (PMPY)

spend for the enrolled group, a 7.7% reduction in inpatient spend PMPY, and an 11.6% reduction in emergency department spend PMPY. The bottom line is that this was a large, carefully constructed study that showed reductions in acute care and overall savings.

There are many other studies from individual pediatric comprehensive complex care interventions that have shown cost savings. They uniformly demonstrate substantial changes in utilization patterns, fewer inpatient hospital admissions and days, reduced emergency department use for most, and increased, appropriate outpatient and pharmacy services. While these studies varied in their CMC population cohort and their service delivery models, their conclusions were consistent. They found value in intensive care coordination and in team-based care that included the active participation of pediatric specialists and subspecialists and a range of other health professionals. A list of many of these cost effectiveness evaluations and a very brief summary of their results is attached as evidence.

Most of the pediatric comprehensive complex care models fit the definition of a health home, a care model for which enhanced federal funding opportunities exist. Both the ACE Kids Act, which singularly focuses on CMC through health home services and a broader system of care, and Section 2703 state plan amendments, which support health homes more generally, offer federal subsidies for a period of time in the form of higher federal Medicaid matching rates. These subsidies, a 90% federal match rate for 2 years under Section 2703 state plan amendments and a +15% federal match rate increase for 2 quarters under ACE Kids, can reduce state and local costs associated with initiating or expanding these models of care. It is notable that a high proportion of CMC are Medicaid enrolled so the impact of these subsidies is more concentrated for CMC than with many other populations.

The bottom line is that adoption of these care models is a financing opportunity much more than a financial risk. To mitigate reservations about this evidence, federal Medicaid policies offer substantial subsidies that can provide time to implement and refine these models, testing them in local markets.

Issues Unique to the CMC Population – Cost Effectiveness Design

The limited number and variation in pediatric comprehensive complex care models has frequently required individual programs to demonstrate cost effectiveness to prove their worth. This creates methodological burdens that rarely are encountered by programs caring for other populations. Some of the technical complications in performing cost effectiveness evaluations for CMC include the small size of the population, its heterogeneity, very high and often volatile healthcare costs, and the difficulty in accurately identifying a matching control group. This latter reason and the limited scope of most demonstrations leads program evaluations to pre- and post-data comparisons. This allows legitimate criticism of reliability and concerns about regression to the mean. These issues, intrinsic to the CMC population, can serve as barriers to adopting, supporting, and advancing these models.

As noted above, the consequences of the health conditions of CMC have impacts in domains and timeframes beyond those usually considered by policymakers and administrators in cost-benefit analyses and cost effectiveness evaluations. These include impacts on family functioning, finances and caregiver health and well-being, cost and benefits accrued by other human services

systems, and life course health, development and costs as the number and longevity of these children increase. The standard practice of looking only at intervention impacts and costs a year or two down the road limited to the healthcare domain is far too narrow for a fair and accurate picture.

CMC have most of their caregiving needs met by their families. The pressures of this caregiving have a profound effect and the impacts extend from the families themselves to other social programs beyond the healthcare domain. The fracturing of families and/or their decreased economic capacity add costs to government services outside of the healthcare space. Food, housing, and other life essentials can easily become an unmet need when the family unit is upended and the parents' capacity for earnings is diminished. Cost effectiveness evaluations in healthcare rarely include these other human services system costs. In that sense, they are incomplete and biased against more robust service responses from the healthcare sector which can potentially mitigate these negative outcomes and other system costs.

As noted above, too often healthcare focused cost effectiveness evaluations extend over a very limited time frame. They routinely look at post intervention costs only a year or two out. This interval makes little sense for CMC who are likely to be reliant on some type of government support through their lifespan. While it is speculative to suggest exactly what form that support might take, the increased need for future support should be intuitively obvious as a general proposition and there are some common examples. During childhood, CMC often require costly special education services. Better health care services and outcomes can reduce some of those needs. As children grow into adulthood, their parents will age and become less able to provide care and support; the needs of many CMC (children becoming adults) will more and more be borne by government. This is not rocket science. Even without long term experience and evidence, a pragmatic approach would be to build systems and services that are comprehensive, taking the long view for the CMC population. This cuts against the grain of our myopic healthcare system payers which generally focus on the immediate future, emboldened by the expectation that many of their enrollees will move to another payer over time.

All of these unique characteristics and circumstances of CMC lead to the conclusion that new forms of service delivery for CMC are necessary but face substantial barriers to obtaining different and more sufficient coverage, benefits, and reimbursement from healthcare payers. Their usual approaches to cost-benefit analyses are inadequate and inappropriate when applied to adopting new models of care for CMC. This misfit creates bias against pediatric comprehensive complex care models which should be recognized and flipped to affirmative action, a presumption of effectiveness.

Issues Unique to the CMC Population – Institutional Recognition and Engagement

There are three primary issues that have led to resistance from health care payers, including Medicaid agencies, to supporting new models of care for CMC: (1) the very small size of the CMC population; (2) the variation in service models across this heterogeneous population; and (3) the investment that health care payers have made in more encompassing and vanilla care models for broader populations where CMC specific and tailored care models are overlooked.

Small populations of patients have difficulty getting attention within the healthcare financing world. It is easy for CMC to get lost within so many covered lives and systems of care. In Medicaid, where there are many unique and high acuity/intensity populations, it is natural to assume that the needs of CMC are already accommodated either by broad systems, such as HMOs, or by special waivers, especially those of the 1915 home- and community-based service variety often designed with adults with disabilities and frail elders in mind.

Developing care systems for the relatively small numbers of CMC is complicated by their heterogeneity; they are not merely a small population, but are a group composed of multiple sub-populations. Consequently, CMC require care systems that are designed to serve different groups. The recent growth of pediatric comprehensive complex care models have been focused on serving the most fragile children often without clear diagnoses. Many of these service models have been developed by clinician champions with different personal experience and perceptions about need and response and who have substantially different levels of institutional support. This variation is accentuated by the range of state and local healthcare environments, especially on an urban-rural continuum. This affects accessibility to pediatric specialists and sub-specialists, the role of PCPs, and resources to organize care. All of this has led to variation in the design of pediatric comprehensive complex care models for the most fragile in terms of both resources and function.

For some few CMC with clear and relatively frequent diagnoses, there exist established evidence-based care standards (e.g., cystic fibrosis, hemophilia, spina bifida). These introduce yet another variation in model design (e.g., a different mix of health professionals comprising the care team) that presents to healthcare payers looking for uniformity for coverage and reimbursement purposes. While this variation may be inconvenient, the availability of these established evidence-based care standards can serve as a foundation for the broader system through functional consistency. Social work is needed across subgroups because of potential issues around social determinants of health, a functional area that should be covered in all cases. However, physical therapy and expertise with specialized equipment may be important for some subgroups but not others.

There also is the matter of managed healthcare entities and the care coordination function that is typically embedded in their operation. Many payers, especially Medicaid, have invested in HMOs, ACOs, and similar structures to coordinate care for their entire enrolled population. At least part of the purpose of care coordination is cost control and can be more accurately labeled “case management”. This investment, with its implicit assumption of effectiveness across the spectrum of enrollees, predisposes Medicaid agencies and their delegate MCOs to resist exploring more tailored alternative models of care and payment. Medicaid has a huge population to serve and it takes considerable resources and energy to build the broad systems and execute the core functions for a generally effective program. There is an understandable inertia for keeping their systems intact that includes delegation of many functions to their HMOs. Adopting the core design characteristics of pediatric comprehensive complex care means asserting authority to assure team-based care with the care coordination function embedded with the direct care team. This takes special effort but can be accomplished through HMO/ACO contractual requirements or carving out the CMC population from managed care and creating these

arrangements directly from the central Medicaid agency. Achieving change for the evolving models of care means upsetting the current order and that is never easy.

The institutional barriers to promoting and adopting improved models of care for CMC can feel discouraging, but they should not be an excuse for inaction. Better designed, organized, and financed programs have been demonstrated to positively impact CMC and their families as well as changing utilization patterns and creating cost offsets. The nature of this very high-cost population, its projected future growth, and the positive evidence for specifically designed CMC systems of care merits the special attention of policymakers and large healthcare institutions.

Conclusion:

While available studies support investments in comprehensive and specialized care of CMC, debates about the rigor of these evaluations and questions about their conclusions will no doubt continue, in part to forestall the need to invest in alternative models of care. However, the current evidence supporting pediatric comprehensive complex care models reliably shows changes in utilization patterns that align with improved care and better outcomes with substantial cost offsets. Cost effectiveness and value, value inclusively defined, should be the basis for adoption of these models, not a narrowly constructed criterion of cost savings. (For contrast, consider the basis for evaluating the “value” of new drugs.) The Triple Aim of health care has three legs - better care, better health, lower costs - not one, so it makes sense to step back from the preoccupation with costs as a singular determinant. The vulnerability of the CMC population and the care needs that fall to their families should justify a more value-oriented basis for improving their service delivery systems.

There are compelling moral and effectiveness arguments for the support of pediatric comprehensive complex care service models. Coverage and adequate reimbursement are needed to sustain existing models and spur the cross-institutional collaboration necessary to further develop and refine best practices and evidence-based standards. This can be accomplished through legislative policy (e.g., the ACE Kids Act) or administrative action by agencies. The impetus for policy change can be through the policy makers and administrators themselves but is likely to require advocacy by those outside of “the system”. Title V Children and Youth with Special Health Care agencies, providers dedicated to the care of CMC, parents, and other advocates all can play important roles in pushing for coverage and adequate reimbursement.

The intent of this paper is to provide current evidence for the effectiveness of pediatric comprehensive complex care service models and to highlight the tremendous challenges facing both families and providers dedicated to improved care and outcomes. The hope is that the information presented is tangibly useful, drawing specific attention to the CMC population and resulting in coverage and financial support for these care models. It is unfortunate that some policy makers and administrators have rigidly insisted on cost reduction to justify coverage of new service models. This is upside down; the dependence of this very vulnerable population of children on the healthcare system should reverse the burden of proof, creating an affirmative bias for forward movement. This population and those committed to serving them deserve it.

Literature On Cost Effectiveness of Models of Care For Children With Medical Complexity

1. ***Costs and Use for Children with Medical Complexity in a Care Management Program:*** David A. Bergman, MD, David Keller, MD, Dennis Z. Kuo, MD, MHS, Carlos Lerner, MD, MPhil, Mona Mansour, MD, MS, Christopher Stille, MD, MPH, Troy Richardson, PhD, Jonathan Rodean, MPP, Mark Hudak

Journal – PEDIATRICS

Location/Setting – 10 Children’s hospital complex care programs from across the U.S.

Conclusions - We conducted a prospective cohort analysis of a population of 4530 CMC enrolled in a learning collaborative designed to improve care for CMC ages 0 to 21 years identified using 3M Clinical Risk Group categories 5b through 9. CMC enrolled in a learning collaborative showed significant decreases in total spending and a significant decrease in the number of hospitalizations and ED visits. Additional research is needed to determine more specific causal factors for the results and if these results are sustainable over time and replicable in other settings.

2. ***Association of a Targeted Population Health Management Intervention with Hospital Admissions and Bed-Days for Medicaid-Enrolled Children:*** David M. Rubin, MD, MSCE; Chén C. Kenyon, MD, MSHP; Douglas Strane, MPH; Elizabeth Brooks, MPH, MSSP; Genevieve P. Kanter, PhD; Xianqun Luan, MS; Tyra Bryant-Stephens, MD; Roberto Rodriguez, MD, MPH; Emily F. Gregory, MD, MHS; Leigh Wilson, MSW, LSW; Annique Hogan, MD; Noelle Stack, MSN, RN, CPN; Kathleen Ward, MSN, CPNP, AE-C; Joan Dougherty, BSN, CPN, CSN; Rachel Biblow, MSW; Lisa Biggs, MD; Ron Keren, MD, MPH.

Journal - JAMA Open Network

Location/Setting - Children’s Hospital of Philadelphia

Conclusions - In this quality improvement study, a population health management approach providing targeted integrated care team interventions for children with medical and social complexity being cared for in a primary care network was associated with a reduction in service utilization compared with an out-of-network comparison group. Standardizing the work of care teams with quality improvement methods and integrated information technology tools may provide a scalable strategy for health systems to mitigate risk from a growing population of children who are eligible for Medicaid.

3. ***Hospital Consultation from Outpatient Clinicians for Medically Complex Children - A Randomized Clinical Trial:*** Ricardo A. Mosquera, MD, MS; Elenir B. C. Avritscher, MD, PhD, MBA; Claudia Pedroza, PhD; Cynthia S. Bell, MS, PhD; Cheryl L. Samuels, RN, PNP; Tomika S. Harris, RN, PNP, DNP; Julie C. Eapen, MD; Aravind Yadav, MD; Michelle Poe, PhD, RN; Raymond L. Parlar-Chun, MD; Jay Berry, MD, MPH; Jon E. Tyson, MD, MPH

Journal - JAMA Pediatrics

Setting/Location - University of Texas Health Science Center at Houston

Conclusions - Children with medical complexity (CMC) frequently experience fragmented care. We have demonstrated that outpatient comprehensive care (CC) reduces serious illnesses, hospitalizations, and costs for high-risk CMC. Yet continuity of care for CMC is often disrupted with emergency department (ED) visits and hospitalizations. Among CMC receiving comprehensive outpatient care, an HC service from outpatient clinicians likely (confidence of over 90% on most statistical measures) reduced total hospital days, hospitalizations, PICU days, other outcomes, and health system costs. Additional trials of an HC service from outpatient CC clinicians are needed for CMC in other centers.

4. ***Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: a randomized clinical trial:*** Ricardo A Mosquera, Elenir B C Avritscher, Cheryl L Samuels, Tomika S Harris, Claudia Pedroza, Patricia Evans, Fernando Navarro, Susan H Wootton, Susan Pacheco, Guy Clifton, Shade Moody, Luisa Franzini, John Zupancic, Jon E Tyson

Journal - JAMA Pediatrics

Setting/Location - University of Texas Health Science Center at Houston

Conclusions – For high-risk children with chronic illness, an enhanced medical home that provided comprehensive care to promote prompt effective care vs usual care reduced serious illnesses and costs. These findings from a single site of selected patients with a limited number of clinicians require study in larger, broader populations before conclusions about generalizability to other settings can be reached.

5. ***A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs:*** Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P.

Journal - Archives of Pediatrics and Adolescent Medicine

Setting/Location - Children's Hospital of Wisconsin

Conclusions - This tertiary care-primary care partnership model improved health care and reduced costs with relatively modest institutional support. Results: A statistically significant decrease was found in the number of hospitalizations, number of hospital days, and tertiary care center charges and payments, and an increase was found in the use of outpatient services. Aggregate data revealed a decrease in hospital days from 7926 to 3831, an increase in clinic visits from 3150 to 5420, and a decrease in tertiary care center payments of \$10.7 million. The special needs program budget for fiscal year 2005 had a deficit of \$400,000.

6. *Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children: Casey PH, Lyle RE, Bird TM, et al.*

Journal - Archives of Pediatrics and Adolescent Medicine

Setting/Location - Arkansas Children's Hospital, Little Rock, Ark.

Conclusions - This hospital-based multidisciplinary clinic resulted in a significant decrease in total Medicaid costs for medically complex children. Results: The mean cost per patient per month decreased by \$1766 for inpatient care ($P < .001$) and by \$6.00 for emergency department care ($P < .001$). Although the cost per patient per month for outpatient claims ($P < .05$) and prescriptions ($P < .001$) increased, the overall cost to Medicaid per patient per month decreased by \$1179 ($P < .001$).

7. *Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-community collaboration: Eyal Cohen, Ashley Lacombe-Duncan, Karen Spalding, Jennifer MacInnis, David Nicholas, Unni G Narayanan, Michelle Gordon, Ivor Margolis & Jeremy N Friedman.*

Journal - BMC Health Services Research

Setting/Location - The Hospital for Sick Children, University of Toronto, Canada

Conclusions - Complex care can be provided in community-based settings with less direct tertiary care involvement through an integrated clinic. Improvements in health care utilization and family-centeredness of care can be achieved despite minimal changes in parental perceptions of child health. Results: Total health care system costs decreased from median (IQR) \$244 (981) per patient per month (PPPM) pre-enrollment to \$131 (355) PPPM post-enrollment ($p=.007$), driven primarily by fewer inpatient days in the tertiary care center ($p=.006$). Parents reported decreased out of pocket expenses ($p<.0001$).

8. *Community Care of NC. Care Management for Medicaid-enrolled Children: Insights for Savings Optimization: C. Annette DuBard, MD, MPH and Carlos Jackson, PhD*

Setting/Location - State of North Carolina

Conclusions - Data Brief: Highly impactable children commonly face social challenges such as poor support systems, unmet nutritional needs, or unstable housing; circumstances which demand a community-based multidisciplinary care team approach to effectively leverage community-based resources. Since 2012, CCNC's strategies have helped to drive down statewide utilization rates for Medicaid-enrolled children: hospitalization rates by 33.1%, emergency department utilization by 11.7%, and readmission rates by 65.7%.

9. ***Children with medical complexity and Medicaid: spending and cost savings:*** Jay G Berry, Matt Hall, John Neff, Denise Goodman, Eyal Cohen, Rishi Agrawal, Dennis Kuo, Chris Feudtner

Journal – Health Affairs 2014, Dec.

Conclusions - Theory article: A small but growing population of children with medical complexity, many of whom are covered by Medicaid, accounts for a high proportion of pediatric health care spending. We first describe the expenditures for children with medical complexity insured by Medicaid across the care continuum. We report the increasingly large amount of spending on hospital care for these children, relative to the small amount of primary care and home care spending. We then present a business case that estimates how cost savings might be achieved for children with medical complexity from potential reductions in hospital and emergency department use and shows how the savings could underwrite investments in outpatient and community care. We conclude by discussing the importance of these findings in the context of Medicaid's quality of care and health care reform.

10. ***What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System:*** Jay G. Berry, MD, MPH Complex Care Service, Division of General Pediatrics, Department of Medicine, Boston Children's Hospital, Harvard Medical School.

Site - Lucile Packard Foundation for Children's Health

Conclusions - Briefing Paper: Discusses cost savings in the context of a range of issues affecting service delivery systems for CMC.

11. ***Impact of the Partners for Children Pilot Program on Medicaid Utilization and Expenditures: Follow-up Report*** Sarah Clark, Lisa Cohn, Sara Schultz

Setting/Location – University of Michigan Health System; Paper delivered to Michigan Department of Health and Human Services, Children's Special Health Care Services

Conclusions – A hospital-based program for fragile CMC featuring home visits by a nurse practitioner and social worker and on-call clinical guidance for parents. Medicaid costs decreased by an average of \$24,000 per year-per enrolled child, largely due to substantial decreases in critical and general inpatient care.

Additional References:

This list includes further citations that, while not directly aligned, are still relevant to the content of the paper, specifically the argument that these models of pediatric complex care programs are cost effective.

1. **Models of Care Delivery for Children with Medical Complexity:** Elisabeth Pordes, MD, MPH, John Gordon, MD, Lee M. Sanders, MD, MPH, Eyal Cohen, MD, MSc.
2. **Better outcomes, lower costs: Palliative care program reduces stress, costs of care for children with life-threatening conditions:** Gans D, Kominski GF, Roby DH, Diamant AL, Xiao Chen, Wenjao L, & Hohe N.
3. **Preventing hospitalizations in children with medical complexity: A systematic review.** Coller, R. J., Nelson, B. B., Sklansky, D. J., Saenz, A. A., Klitzner, T. S., Lerner, C. F., & Chung, P. J.
4. **Effectiveness of a comprehensive case management service for children with medical complexity.** Simon TD, Whitlock KB, Haaland W, et al.
5. **Partners for Kids care coordination: Lessons from the field:** Weier RC, Gardner W, Conkol K, Pajer K, & Kelleher KJ.
6. **New payment model guidance for organizations caring for children with complex medical conditions.** Children's Hospital Association.

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