



# Moving From Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth With Special Health Care Needs

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## ABSTRACT

Children and youth with special health care needs (CYSHCN) use disproportionately more health care resources than non-CYSHCN, and their unique needs merit additional consideration. Spending on health care in the United States is heavily concentrated on acute illnesses through fee-for-service (FFS). Payment reform frameworks have focused on shifting away from FFS, addressing health outcomes and the experience of care while lowering costs, particularly for high resource utilizers. The focus of payment reform efforts to date has been on adults with chronic illnesses, with less priority given to investment in children's health and life course. Spending for children's health is also considered an investment in their growth and development with long-term outcomes at stake, so research questions should focus on where and how such spending should be targeted. This paper discusses high-priority research topics in the area of health care financing for

CYSHCN in the context of what is currently known and important knowledge gaps related to investment for CYSHCN. It proceeds to describe 3 potential research projects that can address these topics, following a framework informed by the priority questions identified in a previous multistakeholder research agenda development process. We focus on 3 areas: benefits, payment models, and quality measures. Specific aims and hypotheses are offered, as well as suggestions for approaches and thoughts on potential implications.

**KEYWORDS:** children and youth with special health care needs; health insurance; quality measures; research agenda; value-based payment reform

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## WHAT'S NEW

We provide recommendations for a research agenda that will help inform the evidence base for testing and improving health care payment reform for children and youth with special health care needs, based on recommendations using a multistakeholder process.

CHILDREN AND YOUTH with special health care needs (CYSHCN) are by definition higher utilizers of health care services than their typically healthy, typically developing peers.<sup>1</sup> They often require health care and related services from a broad spectrum of providers and systems that in turn require effective care coordination to ensure they receive appropriate care and maximize the return on investment (ROI). The 20% of children who have special health care needs comprise 50% of pediatric health care spending,<sup>2</sup> and less than 1% of children typically

comprise 15% to 33% of those health care expenses.<sup>3</sup> As medical complexity increases, known spending drivers increasingly include inpatient and emergency care, medications, specialized therapies, and mental health. Moreover, social determinants of health (SDoH) particularly affect CYSHCN, with most conditions more prevalent and more severe among low-income populations and populations of color, and expenditures for some needs tied closely to SDoH.<sup>4,5</sup>

Health care financing for CYSHCN that directly supports providers and health care systems generally offers inadequate support and incentives for optimal chronic care management. At present, funding mechanisms include direct service provider payments and government, employer, and personal contributions, including insurance premiums and cost sharing. Changes in the mechanism of health care financing can drive incentives in utilization, access, and outcomes for CYSHCN. Payment mechanisms

involve varying degrees of individual versus population-based payments and cover the spectrum from fee-for-service (FFS) to full capitation. A lack of incentives for generating value (defined as benefit per unit cost) in a pure FFS system can contribute to an unsustainable spending trajectory. Frameworks such as the Health Care Payment Learning & Action Network describe payment design that lies along on a continuum from FFS to full capitation can provide opportunities to address quality and value albeit with greater risks to providers and systems.<sup>6</sup>

The term “value-based payment reform” typically refers to creating “value” as indicated by health outcomes, care experience, and lower cost, achieved through changes in health care financing mechanisms including provider incentives, greater accountability and shared risk.<sup>6</sup> To date, most value-based payment reform efforts have been focused on cost-savings with equal or improved outcomes in adults with complex conditions, who comprise a larger population and a greater share of health care spending.<sup>7</sup> For children, few are hospitalized per year even among more complex populations, and children can move in and out of high cost/medical complexity status, so it is not yet known what overall costs are actually preventable on the population level.<sup>8,9</sup> However, spending in childhood also constitutes a long-term investment in improved health and development over the life course as well as in the well-being of parents.<sup>10,11</sup> The optimal financing mechanisms for CYSHCN to achieve improved short- and long-term outcomes, defining value for all stakeholders, and the scope of payment design needed to address SDoH, remain unknown.<sup>12</sup> This paper will broadly focus on health care financing mechanisms, including payment design and policies, while acknowledging the work needed to address broader financing mechanisms that impact SDoH.

### PROCESS FOR IDENTIFYING AND PRIORITIZING A NATIONAL RESEARCH AGENDA FOCUSED ON CYSHCN

In 2017–18, leadership of the Children and Youth with Special Health Care Needs Research Network used an adapted RAND/UCLA Appropriateness Method (RAM) to identify and prioritize topics of focus for a national research agenda to promote optimal health systems for CYSHCN. Participants included families of CYSHCN.<sup>13</sup>

Financing of care for CYSHCN was among the key topics identified by the research agenda development process. At the beginning of the process of the agenda development, 3 priority questions within this topic were identified based on stakeholder-perceived need and urgency, research impact, and family-centeredness. They included, 1) “Which payment models and state CYSHCN organizational structures (eg, increased managed care use, accountable care, bundled payments, attention to social determinants, etc.) most effectively enhance quality of care and CYSHCN well-being?”; 2) “How is ROI for care coordination for CYSHCN best measured, and over what timeframe?”; and 3) “Which value outcomes are meaningful to patients/families, health care providers and payers?”

Usability of these questions in development of specific research projects was beyond the scope of this effort. To enable investigation of these complex questions by CYSHCN researchers requires parsing them into more answerable components and choosing subparts that may be more easily used as a starting point.

### WHAT THIS PAPER OFFERS

The following discussion drills down into some of the more immediately answerable parts of the 3 high-priority questions described in the research agenda development process as viewed through the lens of value, provides a summary of the current knowledge related to them, indicates existing gaps in the evidence base for these questions, and offers recommendations for researchers to begin to address them.

### SUMMARY OF EXISTING KNOWLEDGE ON HEALTH CARE FINANCING FOR CYSHCN

1. Underinsurance is a common problem for families raising CYSHCN, with more than half still covered under private insurance arrangements with variable levels of benefits.
2. Medicaid is a major source of coverage for almost half of CYSHCN as well as a majority of children with medical complexity (CMC). Medicaid managed care is a common financing strategy which may include capitation and an emphasis on care coordination as a mechanism for increasing value.
3. Most of what is currently available in the literature related to identifying opportunities to increase value focuses on models that are based in specific environments (ex: a hospital-based outpatient clinic serving CMC) and which have small numbers of enrolled participants. Identifying the elements of these models that are generalizable to different settings and larger populations of CYSHCN is a prime target for new research.

### CURRENT LITERATURE ON HEALTH CARE FINANCING AND CYSHCN

Health care financing for CYSHCN has evolved over the past 30 years. While most children remain on private insurance, benefits often are fewer or less intense than Medicaid. Accordingly, Medicaid coverage, with its robust benefits and minimal cost-sharing, has increased dramatically to covering almost half of CYSHCN overall, and a majority of CMC.<sup>14</sup> However, underinsurance is still a common problem for CYSHCN, with almost 34% of families reporting their child’s coverage was inadequate in meeting their health care needs in 2018–19.<sup>15</sup> Payment arrangements increasingly include managed care organizations that offer capitation, payments for case managers, or other support for care coordination for CYSHCN, although considerable variation in benefits and payment design remains.<sup>16</sup>

Existing research on CYSHCN financing has often defined value by increased resources to outpatient care

with a return on investment measured by savings from decreased emergency department and inpatient care. Two studies of highly focused outpatient interventions in high-need populations produced positive financial results, while another in a broader population did not produce cost savings but did produce improvements in parent health care quality ratings.<sup>17,18,19</sup> A more population-focused study involved the Partners for Kids Accountable Care Organization, which found a favorable impact of a case manager on CYSHCN care processes and outcomes.<sup>20</sup> Another model currently being tested is the Centers for Medicare & Medicaid Innovation (CMMI) funded Integrated Care for Kids (InCK) model.<sup>21</sup>

Payment mechanisms and value outside immediate health care spending are less well studied. A recent report on a CMMI project offers some perspective on the development of new payment models for CMC, with key actuarial lessons based on the experiences of 10 participant organizations.<sup>22</sup> Standardized utilization definitions and cost data sets were mentioned in the report to better understand patterns of care and the impact of care coordination. Spending related to life course, development, mental health, and health and health care outcomes other than utilization has not been well studied for CYSHCN.

### SUMMARY OF KNOWN GAPS FOCUSED ON THE QUESTIONS RAISED BY THE RESEARCH AGENDA DEVELOPMENT PROCESS

1. Studies that best reflect the relationship among financing models and value, including health care quality and health outcomes for CYSHCN, are underdeveloped.
2. Care coordination interventions hold promise for improving care processes and outcomes, but the best way to include these activities in comprehensive payment models remains unknown; further, the long-term value of care coordination on CYSHCN life course has not been established.
3. Value outcomes are not universally agreed upon by families, the health care system, and payers, making studies of interventions to maximize value difficult.

### CURRENT KNOWLEDGE GAPS FOCUSED ON KEY RESEARCH QUESTIONS

Value-based payment reform often implies a transition from FFS to prospective or retrospective payments for non-encounter-based services. These may include incentive-based capitation payments or even global capitation that may pay for staff and non-encounter-based care, such as practice-based care coordination, supporting care delivery models aligned with chronic care needs.<sup>19</sup> This framework is the foundation of current knowledge gaps for health care financing for CYSHCN.

The first question identified by the initial research agenda development process (*Which payment models and state CYSHCN organizational structures most effectively enhance quality of care and CYSHCN well-being?*) is

difficult to address directly given current knowledge. There is tremendous variation across payers and states in current payment models, as well as support programs for the care of CYSHCN. Moreover, consensus measures of quality of care and CYSHCN well-being are underdeveloped. To begin to answer this question, we need at least some standardized paradigms of each of these constructs. First, more information is needed on the types and amount of payments needed to support chronic care management. FFS models should address appropriate payment level and scope of payments, including family cost-sharing and provider payment, that incentivize care coordination and care navigation. Models that include value-based components need information on payment levels for incentives (eg, per member per month amounts) that would result in locating, hiring, and training of care coordinators and other team members involved in chronic care management, as well as estimates of better value that would result from these activities.

While there is considerable discussion of whether and how CYSHCN should be stratified into different risk groups,<sup>23</sup> use of this for purposes of payment is in its early stages and no known best practice is yet available.<sup>24</sup> Questions include how to identify CYSHCN in risk adjustment strategies, the feasibility of the approach, and how to make such an approach sustainable. Another controversy is whether and how SDoH should be included in risk adjustment strategies to inform payment. Supporters feel providers who attract a disproportionate number of CYSHCN may be protected against being penalized for outcomes outside their sphere of influence by controlling for SDoH. Those who argue against it voice concern that low-performing providers may be “let off the hook” by blaming SDoH for poor outcomes.<sup>25</sup>

The second question identified in the research agenda development process (*How is return on investment for care coordination for CYSHCN best measured, and over what timeframe?*) implies a ROI in the form of reduced acute care costs. The American Academy of Pediatrics identifies care coordination as an essential activity of the medical home that must be appropriately funded<sup>26</sup>; CMMI includes it as an essential activity in alternative payment models and has identified it specifically for children as part of their new InCK model. FFS can support care coordination at the individual level for specific services such as care plan oversight, but the ROI would only accrue to the provider under alternative payment models. Questions continue about where to locate resources and how to pay for care coordination activities.

ROI for CYSHCN has focused on prevention of emergency department visits and hospitalizations are the primary opportunities for cost savings. Both the Coordinating All Resources Effectively Award project conducted at 10 children’s hospitals<sup>27</sup> and the Partners for Kids care coordination project conducted in the context of a large pediatric accountable care organization in Ohio<sup>20</sup> demonstrated decreased inpatient utilization, and the Coordinating All Resources Effectively Award project showed a modest overall decrease in costs. Studies using

more sensitive outcome measures, broader settings, and more rigorous designs such as randomized controlled trials may help elucidate the issue further.<sup>28,29</sup> From a pure cost perspective, enrollees in care coordination programs may see short-term spikes in costs, while previously unmet need for health services is addressed.

Relatively few CYSHCN, however, visit the ED and even fewer are hospitalized in a given year, which reduces the impact of such strategies. In addition, high resource utilizers often show natural clinical improvement or “regression to the mean.”<sup>30</sup> A variety of strategies may be needed to address total costs of care at the system level. More nuanced improved outcomes from care coordination for CYSHCN may accrue over years rather than months, requiring a life course approach for appropriate measurement.

Appropriate measures of health care quality, quality of life, and well-being that can be applied consistently across different populations of CYSHCN are essential to answer the second and the third high-priority question (“Which value outcomes are meaningful to patients/families, health care providers and payers?”). The definition of value and ROI may differ among stakeholders, especially because of the heterogeneous nature of the CYSHCN population and the different meanings of value over time. In Europe, the DISABKIDS project has developed more specific health-related quality of life measurement instruments constructed from child, adolescent, and parents perspectives, addressing child and family impact for both pediatric condition-specific and condition-agnostic uses.<sup>31,32</sup> Further progress on measures has been made in incorporating family perspectives on value<sup>33</sup> and in developing measures of family-centered care.<sup>34</sup> More broadly, formative research on domains of health that are important to CMC (and likely to all CYSHCN) has been done by Barnert et al,<sup>35</sup> who identified a comprehensive list of health outcomes for CMC, a sub-population of CYSHCN. More collaborative work remains to be done that builds consensus among stakeholders as to what is most important and how to measure, with consistent integration of all perspectives, including that of families and patients, into the planning, implementation, and evaluation of outcome measure development.<sup>30</sup> A comprehensive library of measures for child health has been developed by the Maternal and Child Health Research Network and is located online at <https://www.mch-measurement.org/browse/mchmeasurement>.

## SUMMARY OF RECOMMENDATIONS FOR FUTURE RESEARCH

1. Assess value through evaluating the fit between benefit packages and the needs of CYSHCN through comparison of different payment models with typical patterns of need.
2. Develop models to measure ROI for care coordination.
3. Use a multistakeholder process to rank health care value outcomes for CYSHCN.

## PROPOSED FUTURE RESEARCH BASED ON THE QUESTIONS RAISED FOLLOWING THE RAM PROCESS

Challenges outlined in the preceding sections make research studies challenging to execute, but the CYSHCN financing research agenda can start addressing the RAM questions by exploring payment models, ROI for care coordination, and potential value outcomes. The following research questions were developed by the authors following the RAM process and are examples of research questions and related projects that may provide the basis for such an agenda.

### PAYMENT MODELS, QUALITY OF CARE, AND CYSHCN WELL-BEING

A proposed study would examine policies of different payment models and apply them to specific needs of CYSHCN—for example, a crosswalk of defined needs and examination of whether different value-based payment models are likely to meet those needs. The study would take the form of a “tabletop exercise” to describe some features of different alternative payment mechanisms and how they could impact different common examples of CYSHCN.

*Specific aim/hypotheses:* Describe how various proposed alternative value-based payment methods may impact care for CYSHCN.

*Methods:* This would be largely a descriptive study of the range of payment models for CYSHCN. First, the study would provide 5 to 8 case examples of different care and service needs for CYSHCN with a range of practice settings. Then, key characteristics of value-based payment models of coverage and incentives currently being implemented in different Medicaid and/or commercial programs would be extracted. The study would assess how such payment models would address the cases presented, and provide potential recommendations for pilot projects, including definition of CYSHCN risk stratification, selection of variables including SDoH, and outcomes, including health care utilization, improvements in health status, and family-reported measures of satisfaction and reduced financial hardship.

The feasibility and speed of conducting this study would be high since the study is largely descriptive.

*Implications:* Describing the impact of differing and alternative payment models on different paradigms of CYSHCN needs will give initial insight into how they might (or might not) support key needs, pilot programs, and sustainability. Next steps could include a more in-depth observational study, using data from the initial study to refine aspects of the payment models to examine, outcome measures that might be meaningful and sensitive to change, and more sophisticated measures that can examine quality of care and CYSHCN well-being at the individual level. Experimental designs might then examine implementation of a particularly promising payment model and might use quality improvement research methods to determine how best to refine it to meet the needs of CYSHCN populations over time.

## RETURN ON INVESTMENT FOR CARE COORDINATION FOR CYSHCN: HOW AND OVER WHAT TIMEFRAME TO MEASURE IT BEST

This research question is challenging because of variations in the accepted scope and definition of care coordination, from personnel qualifications, staffing considerations, and scope of duties.<sup>36</sup> The ROI depends not only on the scope asked of the activities that are defined, but also where the ROI accrues, which may lie outside the scope of a clinical practice (eg, reduced hospital admissions, whose savings may not accrue to the practice) or even the traditional health care system (eg, ability to attend school consistently)<sup>37</sup>, and the time horizon for the ROI, which can be lengthy from a life course perspective. Nonetheless, it is an important question, and selecting one aspect that might be feasible even if less than ideal would be useful.

This study could begin with a care mapping framework for CYSHCN examples that examines all determinants of health, to assess the scope of necessary care coordination needs.<sup>38</sup> Considerations could include funding and operations and encompass coordination of activities related to health care but also SDoH, family support, and wellness. It would then examine available examples of outcomes from relevant care coordination activities (eg, met health care needs, food security, and school attendance).

*Aim:* Determine annual costs of care coordination, using an expansive, consensus definition with clear information on service inclusions, across multiple examples and groups of CYSHCN, and determine relative outcomes that would comprise ROI for these coordination activities.

*Methods:* The input would be either care coordinator staff or care coordination activities by established staff, using a care coordination measurement tool.<sup>39</sup> Synthetic costing using health system data, and (if available) data from the education system and other systems outside the health care sector, would be conducted. Outcomes could be strictly financial across service sectors, including savings on low value services and dollars spent on value-added services such as education, or include quantifiable returns not strictly linked to costs such as those described above.

*Feasibility:* This study's feasibility would depend largely on the ability to determine reliable input and outcome measurements, and some may be imprecise. However, prior studies on care coordination ROI have been narrowly defined including data from the health care sector. Use of an integrated care framework, including data from multisector models including Medicaid or InCK, would yield a broader picture of ROI.

*Implications:* Defining the scope of duties and ROI on care coordination is important as systems and funding move toward integration. Studies that examine the fuller scope of care coordination activities, not limiting input nor output to practices or health care but rather across systems, will aid in understanding the true ROI and impact.

## DETERMINING WHICH VALUE OUTCOMES ARE MOST MEANINGFUL TO PATIENTS, FAMILIES, HEALTH CARE PROVIDERS, AND PAYERS

"Value" has different meanings to different stakeholders at different times in the care of CYSHCN. Understanding of the range of desirable value outcomes among patients/families, health care providers, and payers impacts financing design. While important dimensions of health have been determined for certain populations like CMC through ranked-choice and similar studies,<sup>32,40</sup> the cost component of value has not been examined. A qualitative study that describes and ranks value outcomes for CYSHCN among multiple stakeholders would help to inform other key questions by elucidating outcomes for ROI in new investments for CYSHCN.

*Aim:* To assess ranking of key outcomes for CYSHCN, using established lists, by several stakeholder groups.<sup>32, 37</sup>

*Methods:* Qualitative study using a multiple ranked choice method. Respondent groups of parents, health care providers, public and commercial payers, educators, service providers, and disability groups would be organized. Key outcomes as determined by previous studies would be provided, with a human-centered design facilitated approach to develop additional outcomes of interest.<sup>41</sup> A ranking exercise for each group would be undertaken, and analysis would examine similarities and differences in ranking between groups.

*Feasibility:* The feasibility of this study would be high, as this is a qualitative study with the right motivated groups. The study could be conducted virtually as well. Of course, the usability of results might depend on the degree of agreement between different groups and the ability of differing views to be reconciled.

*Implications:* Achieving value in health care is highly dependent on several factors but 2 of the most important are paying the right amount of money for the right kind of care. Determining what is "right" and possibly creating a blended value outcome meaningful to all stakeholders will help identify those value targets specific to CYSHCN.

## CONCLUSIONS

Within the current imperative in the United States of decreasing costs while improving outcomes, care and outcomes for CYSHCN must be studied in order to include them in financing reforms. While CYSHCN do not constitute a large percentage of overall health care spending, it is especially critical to improve their outcomes, as healthy children are more likely to become healthy and productive adults.

A research agenda for health care financing that is targeted specifically to the needs of CYSHCN, their families and providers, which includes robust patient/family engagement in its design, implementation, and evaluation, can help build the necessary evidence base for health care financing innovations and strategies that address these challenges. While conducting this research in a rigorous, highly valid way is formidable, challenges are not

insurmountable. The research questions described here are starting points for health care finance research that describe the landscape of payment models, ROI, and meaningful outcomes to CYSHCN, their families, and their providers and systems. Federal and foundation investments can include support for broader health care financing studies that emphasize patient and family partnership in design, system and statewide model testing, and cross-sector outcomes. These strategies can be addressed in a gradual but systematic manner to produce an evidence base that will quantify the essential elements of health care and related activities for CYSHCN and provide a basis for financing innovations that make sense for this important population.

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