Statement of the Problem: Health Reform, Value-Based Purchasing, Alternative Payment Strategies, and Children and Youth With Special Health Care Needs

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abstract

There is increasing interest in maximizing health care purchasing value by emphasizing strategies that promote cost-effectiveness while achieving optimal health outcomes. These value-based purchasing (VBP) strategies have largely focused on adult health, and little is known about the impact of VBP program development and implementation on children, especially children and youth with special health care needs (CYSHCN). With the increasing emphasis on VBP, policymakers must critically analyze the potential impact of VBP for CYSCHN, because this group of children, by definition, uses more health care services than other children and inevitably incurs higher per person costs. We provide a history and definition of VBP and insurance design, noting its origin in employer-sponsored health insurance, and discuss various financing and payment strategies that may be pursued under a VBP framework. The relevance of these approaches for CYSHCN is discussed, and recommendations for next steps are provided. There is considerable work to be done if VBP strategies are to be applied to CYSHCN. Issues include the low prevalence of specific special health care need conditions, how to factor in a life course perspective, in which investments in children's health pay off over a long period of time, the marginal savings that may or may not accrue, the increased risk of family financial hardship, and the potential to exacerbate existing inequities across race, class, ethnicity, functional status, and other social determinants of health.

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There is increasing interest in maximizing value in health care purchasing by promoting delivery and payment strategies that emphasize cost-effectiveness and achieving the best health outcomes possible given available resources. Payment reform provisions in the Affordable Care Act (ACA) promote value-based purchasing (VBP) strategies to achieve the Triple Aim of lower cost, increased efficiency and improved population health.[1] However, although VBP program sponsors, such as employers or health insurance plans, may have accrued a record of the outcomes associated with these strategies, this information is not generally available to public policymakers for use in designing and implementing VBP programs[2] and so evidence-based strategies for VBP for children are not widely available. Moreover, there is not 1 definition of VBP, and there is a growing landscape of purchasing and insurance design strategies that include innovative financing approaches including bundled payments, accountable care organizations (ACOs), and integrated care systems that link primary care and behavioral health services, among others.

To date, VBP programs have largely focused on adult health, because adults account for a disproportionate share of all health care spending. In 2010, children ages 0 to 18 comprised 25% of the US population, whereas their personal health care expenditures accounted for 13% of spending. In contrast, adults over age 65 comprised 13% of the population and 34% of personal health care expenditures.[3] Given this imbalance, the potential for achieving cost and quality improvements by using VBP for children is hindered. Moreover, children's health care is provided in the context that childhood spending constitutes a long-term investment, which in turn sets the stage for life course health and development.[4] As a result, the benefits of VBP for children may not be realized for decades. Without any evidence, the impact of VBP program development and implementation on vulnerable populations, including on CYSHCN, especially those with medically complex conditions, is unknown.

With the increasing emphasis on VBP, policymakers must critically analyze the potential impact of VBP for CYSCHN, because this group of children, by definition, uses more health care services than other children.[5] According to the 2009/2010 National Survey of Children with Special Health Care Needs, there are ~11 million children who meet this definition or 15% of the total population of children under the age of 18. And, CYSHCN are now less likely to have private coverage than in previous years. Although the total percentage of CYSHCN who are insured has stayed relatively stable over the past 10 years, the source of their coverage has shifted significantly from private to public coverage.[6] In the same survey from 2009/2010, 52.4% had private insurance, 35.9% had Medicaid or Children's Health Insurance Plan, roughly 8% had private insurance as their primary source of coverage and Medicaid as a secondary source, and 3.6% were uninsured at the time of the survey. These data predate the full implementation of the ACA. Although coverage gains for children in general have been observed, the impact of the ACA has yet to be quantified specifically for CYSHCN.

Another challenge related to VBP and CYSHCN is the low prevalence of many specific special health care needs or conditions, which impedes volume purchasing. Using the *International Classification of Diseases, Ninth Revision* standard, children with special health care needs tend to scatter among many different diagnoses, which fall under broad categories such as asthma and other respiratory problems, genetic disorders and congenital anomalies, mental/behavioral health issues, and developmental disabilities, including autism.[5] This distribution is in contrast to the much larger numbers of adults that tend to cluster among a smaller number of specific diagnoses, such as heart disease/stroke, cancer, diabetes, and arthritis; these diagnoses more easily lend themselves to evidence-based chronic disease management.

In the sections that follow, we provide a history and definition of VBP and insurance design, noting its origin in employer-sponsored health insurance. We discuss various financing and payment strategies that may be pursued under a VBP framework. The relevance of these approaches for CYSHCN is discussed and recommendations for next steps are provided.

WHAT IS VBP?

VBP includes a set of health care payment and health delivery strategies that emphasize cost-effectiveness and achieving the best possible outcomes given available resources. In this section of the article, we provide a brief overview of the origins of VBP, provide some examples of VBP strategies currently in use, and discuss the evidence to date on outcomes associated with VBP.

Employer Origins

VBP, especially for Medicare, has been promoted by the ACA beginning early after the law was passed in 2010. However, VBP programs were initiated by employers before the ACA took effect, such as the program begun by Pitney Bowes in 2002.[7] VBP is thus another example of employer-sponsored initiatives, begun in the last several decades, aimed at achieving value in health benefit provision for employees.[8] This most recent initiative has employers asking health plans to achieve both

cost and quality outcomes.[9] Although VBP strategies have been used by employers for many years, there is little published data about the results of these efforts, primarily because the initiatives are being implemented in the private sector. Some results suggest that VBP is more likely to be implemented by larger employers or employer collaboratives,[9] who likely have more purchasing power to incentivize health plans to drive cost and quality outcomes. There is also a cost to implementing VBP programs, such as the need to identify and implement measures of quality, as well as the need to educate employees to make them "smart buyers" of health care. Large employers are more likely to have the resources to develop and support this needed infrastructure.[9]

For VBP to be effective, employers must have access to and use cost and quality data. Robst et al[10] examined survey findings to determine whether employers knew the results of the quality measures available to them. Larger employers were more likely to know the quality measures of their health plans, although a majority of all employers did not know this information.[9]

Under VBP, employers are responsible for making decisions on the basis of the results of data analysis associated with estimating cost and quality outcomes. Benefits managers in private employer human resource departments may decide not to pay for services that are determined to be high cost or low quality, without the counterbalancing positive outcome, and these decisions may be controversial within the company.[7] Without good data to justify benefit design decisions, the uncertainty about the impact of VBP may diminish decision-makers' enthusiasm for taking on the controversy. Some data suggest that the impact of VBP and value-based insurance design (VBID) may vary across benefit design options for different conditions. As a result, employers may not be best served by a "one size fits all" VBP approach, further complicating the employer strategic benefit design choices.[7]

Employers must also be prepared for the unintended consequences of VBP strategies in various health plan designs. For example, under VBP, as well as other health plan designs, costs may be shifted to the employee and result in increases in out-of-pocket expenditures. This outcome may have devastating consequences for those at the low to moderate end of the pay range, or if the employee has a family member with high health care needs, such as families of CYSHCN.[11] Because the largest share of CYSHCN are covered under employer-sponsored health insurance, increases in out-of-pocket expenditures may be associated with the move to VBP for families of CYSHCN.[6]

APPROACHES TO VBP

A number of strategies have been implemented under the general framework of VBP. In this section, we provide brief descriptions of various models used to achieve value in health care purchasing.

Value-Based Insurance Design

A specific type of VBP is VBID. Chernew and Fendrick[12] have identified 2 general approaches to VBID programs: 1 targets services that are especially cost-effective, such as specific medications, and the second targets groups of patients who are likely to respond to selected treatments, such as people with type II diabetes.[13] For these 2 overall strategies, VBID programs use financial or program incentives to encourage patient behaviors, thus reducing overall health care costs, even if the VBID program requires some additional expenditures.[14] For example, Choudhry et al[15] found that VBID programs that used selected pharmacy benefit management strategies, such as mail order pharmacy, demonstrated greater patient medication adherence and lower cost sharing. There is some evidence that VBID can improve medication adherence by lowering or eliminating patients' payments for some medications, although the longer-term business case for VBID has still not been made.[14]

VBIDs frequently lower consumers' cost sharing to motivate healthy behavior, such as adhering to medication regimens. Few health care purchasers have followed the more controversial approach of using increased cost sharing to reduce demand for high-cost, low-value medical care.[16] A lingering question, however, is whether risk, responsibility, and rewards are being equitably shared among families, providers, and payers under plans that include VBID.[17]

Pay for Performance

VBP is also pursued through Pay for Performance (P4P) strategies, which offer financial incentives for provider performance measured against a standard set of metrics, including quality outcomes. A key concern with P4P strategies is the lack of specific quality outcome measures, and performance is often assessed against process measures.[18] Further, there is not consensus in the design or effectiveness of the programs although programs that are more likely to be effective have a specific focus on individual providers and greater communication about the program.[19] There are few studies that have focused on the impact of P4P for children's health,[19] and there is not consistency with respect to the outcome measures that are used.[18] Evidence about the impact of P4P is mixed, and efforts to determine impact have been hindered by confounding from other innovations that were being implemented simultaneously.[2]

Capitation and Bundled Payments

Beyond specific strategies that have been identified as VBP, other financing and purchasing strategies that advance the Triple Aim and may impact CYSHCN are being implemented in an effort to achieve value, including capitation or bundled payments. It has been suggested that bundled payments are a key strategy for achieving value in health care purchasing.[20] The Medicare Payment Advisory Commission endorsed bundled payments, noting the intent of this method: to decrease spending by reducing the number of unnecessary physician services during a hospitalization; to encourage more judicious use of health care resources during the hospital stay; and to reduce postdischarge costs, including unnecessary postacute care services and avoidable readmissions.[21] Medicaid programs have long advanced agendas that include use of capitated purchasing for children's health. However, the impact of these payment systems on CYSHCN has not been documented, and the incentives to withhold or provide less expensive care under capitation are powerful, with potentially devastating consequences for CYSHCN and their families, especially for children with more complex conditions. One solution to this issue is the development of risk adjustment strategies to "level the playing field" among capitated plans. However, the development of accurate risk adjustment strategies has not kept pace with the trend toward moving to bundled payments.

High-risk/high-need patients, such as CYSHCN, are particularly vulnerable to underservice, if provider payment reforms are not linked to meaningful quality outcome measures.[22] Inadequate payment rates that do not cover the costs of serving high-risk/high-need patients may cause providers to skimp on necessary services or avoid serving vulnerable patients entirely. Risk adjustments or patient exclusions are relevant for all the provider payment reforms described in this article, but attention to those issues is critical when payment innovation methods replace rather than supplement known fee-for-service reimbursement mechanisms. Not surprisingly, bundled payment rates and ACO payment methods are usually risk-adjusted to account for differences in severity or other patient-level characteristics, and some high-risk populations may be completely excluded from these arrangements. However, the accuracy of those adjustments and exclusion methods remains uncertain for children and require additional evaluation.[19] Accurate risk adjustment strategies may encourage health plans to offer access to the robust provider networks needed by CYSHCN, limit discriminatory practices, and promote early identification of CYSHCN to control costs and increase quality.

Accountable Care Organizations

The ACA included provisions for the development of a new type of payment strategy: the ACO. The ACO model is intended to promote care integration and provides financial incentives (shared savings) for improved outcomes including quality.[23] Like other VBP strategies, there is little evidence about the impact of ACOs, especially with respect to quality of care.[2] Moreover, ACOs are nearly uniformly being used for adult populations and there is little information about how this strategy might be applied to children.[19] The opportunity for shared savings on the basis of efficiencies in pediatric care is small, including for CYSHCN. And the return on investment for care coordination provided to CYSHCN has not been estimated.[24]

High-Deductible Health Plans

The ACA provides a framework for high-deductible health plans (HDHPs): health care coverage options that offer lower premiums but higher deductibles than typical plans.[25] HDHPs are appealing to subscribers that have few identified health care needs, because the associated short-term out-of-pocket costs are an incentive to enroll. However, for individuals and families with higher health care needs, these plans are associated with increased out-of-pocket costs and potentially, financial hardship associated with health care spending. Family financial hardship resulting from increased out-of-pocket costs associated with the greater health care needs of CYSHCN may impact families of CYSHCN disproportionately.[26] Thus, although HDHPs may be included in the set of options considered for VBP designs, for CYSHCN, this strategy has potentially devastating consequences, especially in the absence of adequate quality and outcome measures that can be used to assess value.[25]

THE EVIDENCE ABOUT VBP

A recent report produced by the Government Accountability Office[27] found little impact of Medicare's hospital VBP program (HVBP). For the most part, the quality measures that were evaluated did not change, the exception being the readmissions indicators that are subject to financial penalties, rather than financial rewards. Interestingly, hospital leaders who were interviewed for the report suggested that any changes that were seen were a result of the hospital's ongoing quality improvement efforts that were in place before the VBP program. As mentioned previously, interviewees described limitations associated with information technology adaptation, which impede efforts to obtain and use outcome measures.[27] Another

study confirmed these results, and noted that the timing of the financial incentives in Medicare's HVBP was not associated with improved quality of care. It is unclear whether improvement for the clinical process measures before the start of HVBP was driven by the expectation of the program or was the result of other factors.[28] These results suggest that, even though VBP programs are moving forward, there is little evidence base on which to build these advancements. We still know little about how best to design and implement VBP programs to achieve stated goals.[2,18] And, the information we do have does not apply to children and especially not to CYSHCN.

VBP AND CYSHCN

Interest in VBP is occurring at a time of great activity and policy focus related to health reform. These other related trends impact health systems and outcomes for CYSHCN and their families, and may interact with implementation of VBP strategies. We identify some relevant trends and discuss their implications for efforts to increase value in health care for CYSHCN.

A key trend impacting VBP and its application to CYSHCN is the increasing number of children with special health needs; the population is growing due to medical advances, epidemiologic changes, and increasing social risk factors. According to the 2001 National Survey of Children with Special Health Care Needs, 12.8% of children in the United States under the age of 18 had special health care needs; 10 years later, the proportion had risen to 15.1.[29] Greater numbers of CYSHCN mean steadily increasing spending on their health care needs. For example, preterm births have increased over 35% in the past 25 years. Although survival outcomes have improved for premature infants, the risk of on-going neurodevelopmental and other health-related issues is still present and can be significant, depending on gestational age and birth weight. The average cost of all medical care for premature infants in the first year after birth has been calculated at approximately $32 000, compared with $3000 for a full-term infant.[30]

In addition to increasing costs directly related to pediatric health care, some costly chronic illnesses in adults have their origin in childhood, which can be avoided or ameliorated through primary prevention strategies. Examples of contributors include obesity, unaddressed mental/behavioral health needs, and the development of risk behaviors in adolescence such as engaging in unsafe sex, tobacco use, or alcohol and substance abuse. As a result, VBP strategies include primary prevention strategies, which when implemented in childhood for all children (including CYSHCN), are key to maximizing adult health. If health issues can be eliminated or improved upon earlier in life, overall costs across the lifespan should be lower. The ACA has opened pathways to preventative services through a provision (Section 2713) that requires private insurers to pay for preventive services without cost sharing, including the pediatric-specific services recommended in the American Academy of Pediatrics' *Bright Futures* initiative.[31] There are many connections to the needs of CYSHCN in *Bright Futures*, including guidance on supporting families, advocating for community-based services, and screening for medical, developmental, and behavioral health needs.

The ACA also established the Prevention and Public Health Fund, through which a broad range of evidence-based initiatives and activities aimed at increasing the effectiveness of the national health care dollar have been implemented. However, investments specific to the population health needs of children in general under the Fund have been limited as compared with those aimed at adults and not primarily focused at CYSHCN. The Fund has also been the frequent target of cuts over the years since its establishment. Greater investment in prevention strategies specifically tailored to the needs of CYSHCN could make a meaningful contribution to controlling costs in both pediatric and later adult health care spending.

The Patient-Centered Medical Home is a model of primary care that is a cornerstone of the delivery reform efforts in the ACA. As conceptualized by the American Academy of Pediatrics, a medical home is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Its goals include improving the quality of care through team-based care coordination, increasing access to health care services and supports, and improving patient engagement and partnership. These goals align intuitively with the goals of VBP; however, components of the medical home critical to CYSHCN such as care coordination have not been consistently included in VBP initiatives to date.

Although over time individual therapies and health care interventions have become more effective and thus, more value driven, the extensive array of continuing health care needs facing CYSHCN are difficult for families, physicians, and other health care providers to manage and coordinate without additional supports. Children with special health care needs often interact with a variety of different systems which are not designed to communicate easily or effectively with one another. Budget issues, lack of integrated or compatible electronic systems to speed communication, and challenges over "turf" are examples of system design flaws

that all impact quality of care and outcomes.

Although care coordination is an essential service and sustainable funding continues to be a primary challenge, care coordination alone is not the answer. A currently underfunded system of care coordination, when it does exist, presumes there is care to coordinate, which is not always the case, especially for families in rural communities, those in plans with inadequate provider networks, and those who require services that are impacted by long-standing workforce shortages, like home nursing and personal care attendant services.[32] Delivery reform, such as the patient-centered medical home and its essential reliance on care coordination, must be linked more directly with VBP payment reforms such as risk-adjusted bundled or global payments to more effectively leverage the benefits of both, thereby fulfilling the Triple Aim as promulgated by former Administrator of the Centers for Medicare and Medicaid Services Donald Berwick, MD, MPP.[24]

INCREASING ATTENTION ON PEDIATRIC MEDICAL COMPLEXITY

Children with medical complexity require health services from a variety of providers and at a high level of intensity; they rely on costly services and supports and their care needs are long-term. As a result, the relatively small population of children with medical complexity, depending on how narrowly or broadly they are defined, is said to be responsible for ~15% to 33% of health care spending for all children.[33]

The broad definition of CYSHCN is not easily operationalized in administrative or claims databases that can then be used to implement VBP programs. Interest in a subset of the population of CYSHCN that can be identified has thus increased, and this group largely includes children with medical complexity. However, payers, providers, state agencies, families, and others conceptualize medical complexity in different ways. This lack of a definitive, consensus-driven picture of the population has made it challenging to initiate effective policy change on a broad, systemic level. Efforts to date have tended to segment the population into different categories, depending on the interests and needs driving how the definition is operationalized. Each decision on how to quantify children with medical complexity has consequences with regard to the number of patients served, resource allocation, quality, cost, and reimbursement—all critical components of VBP.[34]

Factors most often used to define medical complexity in children include[35]:

- Chronic, severe health conditions
- Substantial health service needs, including the use of medical technology
- Major functional limitations
- High health resource utilization

There is no single definition of children with medical complexity. As a result, estimates for how many children have medically complex conditions range from 0.4% to 0.7% of the pediatric population.[36–38] Most sources in a recent review of the literature used 0.6% as an estimate. Although smaller in number than the broad population of CYSHCN, the subpopulation of children with medical complexity have more intense health care needs that may offer opportunities for improved care delivery and enhanced value, through strategies such as care coordination.

VBP AND HEALTH CARE INEQUITIES

Without reliable and valid outcome measures, there is an associated risk that VBP programs will not mitigate and may exacerbate existing health inequities. Children with medical complexity, a subpopulation of CYSHCN, are especially vulnerable to inequities in health care access and outcomes. In 1 example, a 2014 study comparing health and health care access for CYSHCN and those who were medically complex revealed that medically complex children were at least twice as likely as CYSHCN to have at least 1 unmet need for health care, despite their intensified need. The primary determinant of this disparity was the simple presence of complex needs, even among those children with favorable social determinants of health.[39]

The financial incentives that are an essential element of VBP encourage biased selection of less complex cases, and without adequate risk adjustment protections, certainly do not encourage providers to address the social determinants of health that drive some health inequities.[40] VBP includes the provision that more costs are shifted to the consumer, especially in the context of HDHPs. However, for low income families, costs are a barrier to care, as demonstrated in a study of children with asthma.[41] Moreover, family financial hardship is already a critically important issue among families of CYSHCN.[6] There are few protections for this specific type of health inequity, and VBP will not mitigate the problem of family financial hardship as a result of a child's special health care need.

MEASURING VALUE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS, INCLUDING THOSE WITH MEDICALLY COMPLEX CONDITIONS

To implement VBP, payers need information about health outcomes for covered lives. Two constraints limit this essential aspect of VBP strategies. First, there are not broadly accepted and used measures of quality, especially for CYSHCN.

The Children's Health Insurance Program Reauthorization Act of 2009 mandated the Pediatric Quality Measurement Program. Through this initiative, various measures of quality have been identified such as the Consumer Assessment of Healthcare Providers and Systems and the National Research Corporation Picker Pediatric Inpatient Survey.[42] However, these measures are not consistently used across the range of providers, thus making it difficult to design a VBP program on the basis of these measures. More work is needed on the validity and reliability of existing measures, as well as the implementation of expanded measures, such as characteristics of the medical home.[43] Better measures of care integration, care coordination, and integration of mental, developmental, and physical health into a comprehensive care system within the medical home are high priority topics for measure development.[44]

Second, even if measures are agreed upon, developing strategies to gather and analyze the measures is a significant barrier. Information about health outcomes is contained in health records, but if the records are electronic, there are likely to be compatibility issues among the different health information systems. And, the specific data elements needed to determine "value" may not be easily retrieved from electronic medical records. Resolving this barrier will require a significant investment on the part of payers, providers, information systems, and other stakeholders to create and implement standard strategies for health information.[45] These issues become even more complicated when applied to Medicaid claims data, which vary by state and are also subject to significant delays in processing.[46] Without consistent and agreed upon quality and outcome measures, providers will not be able to meet benchmarks and performance incentives as required by VBP to manage patient care and financial risk.[47]

Existing health care quality measures mainly focus on adults with chronic illnesses. Pediatric-specific quality measures do exist, such as those developed under the Children's Health Insurance Program Reauthorization Act of 2009.[48] However, they are geared more toward the general population of typically healthy children and those with broad special health care needs, versus those with medically complex conditions. Some general pediatric measures may actually be inappropriate or misdirective for assessing the quality of care in children with medical complexity, such as immunization rates and hospital readmissions. In the 2015 Core Set of Children's Health Care Quality Measures for Medicaid and Children's Health Insurance Plan, only 1 measure can be linked directly to children with medical complexity (pediatric central line-associated bloodstream infections in the NICU and PICU).[48] Development of quality measures, including those related to functionality such as school attendance, that are specific to CYSHCN and children with medical complexity, will help policy makers use appropriate data to make evidence-driven, well informed decisions.

Value Outside the Doctor's Office or Hospital

Although legislative and societal trends have increasingly supported home and community-based care for individuals with a broad array of disabilities and the evidence regarding the benefits grows, the financial resources required to support it have not kept pace. The system of home and community-based services is chronically underfunded and workforce shortages (particularly in home nursing care) continue. Low reimbursement rates are a primary contributing factor to both of these problems.[32] Waiting lists are common and impact substantial numbers of individuals; in 2010, approximately one-third of all US children, adolescents, and adults with intellectual and developmental disabilities were on a waiting list for some form of home and community-based services.[49] VBP initiatives that include consideration of the cost-effectiveness of home- and community-based services and supports (compared with those exclusive to expensive hospital-based care) hold promise for improving the system as a whole.

Social risk factors can have a significant impact on the value equation in health care services, with important implications for improving quality and reducing cost, but are often underrecognized in defining the population of CYSHCN and children with medical complexity, as well as in formulating policy objectives related to value. Social risk factors include poverty and financial hardship, lack of appropriate, affordable community-based services and supports, deficits in caregiver capability, and the sequelae of racial/ethnic/socioeconomic inequities.

The current system of home- and community-based care depends substantially on family caregiving to support it. The ability of families to meet the responsibilities that gaps in the system impose on them is dependent on a variety of factors, including sufficient financial resources, availability of meaningful social supports, both general and health-related literacy, fluency with both spoken and written English, as well as robust mental and physical caregiver health, to organize, provide, and maintain the care and supports their child requires. Research on challenges faced by families caring for more medically complex children revealed substantial efforts expended by them on care coordination as well

as direct medical care, with the result of financial hardship, compromised gainful employment, and increased stress.[37] Children whose families experience challenges in any or all of these areas are at increased risk for poor health outcomes and increased costs, including expensive permanent institutional care.[50]

Role of Additional Dimensions of Quality and Value

Improving the quality of care for CYSHCN, especially those with medical complexity, is often assumed to hold promise for reducing costs, although this theory is as yet unproven and generalizing what few cost savings revealed in models to date to this heterogeneous population has been challenging, given the specificity of setting, referral process, and reimbursement structure.[35] Measuring quality for this vulnerable population is yet another challenge, as few indicators to date are specifically dedicated to their needs. Targets for future work in improving quality and reducing costs may include avoiding medically unnecessary hospitalizations and/or emergency department utilization, improved management of pharmaceuticals, and patient safety initiatives.

Although a primary concern for many, cost savings is not the only opportunity for improvement under the general heading of quality. High utilization and attendant high costs might be appropriate for many CYSHCN, especially those with medically complex conditions. The transformation of health care delivery systems and payment mechanisms to those that emphasize and reward value is gaining both traction and momentum. Identifying and increasing cost-effectiveness (getting better "bang for the buck") versus simple cost-savings is an additional topic that is ripe for further research and analysis by the health policy community.

Additional dimensions of quality and value to consider from the perspective of CYSHCN include ethical ones, in the context of fairness and justice. Are incentives under VBP strategies being designed in such a way that all clinicians, including pediatric primary care providers and specialists, have an equal opportunity to share in them? For example, if quality measures are only focused on important but routine child health indicators like immunization or readmission rates, will providers with higher numbers of CYSHCN, who require additional time and resources, in their patient panel be disadvantaged under pay-for-performance initiatives? Plans that incorporate VBID must have adequate protections, such as risk or complexity adjustment strategies, built in that recognize clinical nuance—the concept that health services do not produce the same benefit in every patient and that benefit is dependent on who is receiving it, who is delivering it and the setting in which it is being delivered. Robust benefit exception policies and appeals processes are necessary to ensure the unique needs of this vulnerable population are not lost.[17]

CONCLUSIONS

Value-based health care purchasing is not a new idea,[8] but it has received renewed interest in large part due to provisions in the ACA. The evidence base for VBP strategies is relatively weak, and what does exist targets primarily adult health. There are few examples of VBP strategies applied to children and none applied to CYSHCN. Although health policy in the United States is still searching for the "Holy Grail," we have not found it with VBP.[51] That said, moving our focus to include quality and other patient outcomes as a condition of health care purchasing makes intuitive sense. And, if purchasing strategies, such as ACOs, promote care integration, then payment reform is an idea worth pursuing.

The ACA holds significant promise for improving access to health care through new and existing pathways to health insurance coverage. Many of the consumer protection provisions, for example, have particular relevance to CYSHCN. The removal of lifetime and annual cost limits is particularly beneficial to those with expensive, chronic conditions and service needs. Parents with employer-sponsored coverage who worried about changing jobs because their child might become uninsurable under a preexisting condition exclusion no longer face this barrier to promotions and career changes. A specific provision in the ACA (Section 2302) allows Medicaid-enrolled children who qualify for hospice care on the basis of a 6-month limited life expectancy to also continue to receive curative care at the same time.[52] Although these provisions and others are important steps in improving access to health care for all populations, issues specific to CYSHCN warrant further consideration and new research on their consequences. The ACA was primarily designed to improve access to coverage for the uninsured; how the emphasis on broad versus deep coverage will impact CYSHCN as a population remains to be seen.

There is considerable work to be done if VBP strategies are to be applied to CYSHCN, without further compromising their health status or exacerbating already increasing costs of their care. Issues include the low prevalence of specific special health care need conditions, how to factor in a life course perspective, in which investments in children's health pay off over a long period of time, the marginal savings that are likely to accrue, the increased risk of family financial hardship, and the potential to exacerbate existing inequities that span race, class, ethnicity, functional

status, and other social determinants of health.

ABBREVIATIONS

ACA: Affordable Care Act
ACO: accountable care organization
CYSHCN: children and youth with special health care needs
HDHP: high-deductible health plan
HVBP: hospital value-based purchasing
P4P: Pay For Performance
VBID: value-based insurance design
VBP: value-based purchasing

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