

The Eye of the Beholder: A Discussion of Value and Quality From the Perspective of Families of Children and Youth With Special Health Care Needs

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abstract

There is broad agreement that increasing the cost-effectiveness and quality of health care services, thereby achieving greater value, is imperative given this country's current spiraling costs and poor health outcomes. However, how individuals or stakeholder groups define value may differ significantly. Discussion of value in the context of health care, in particular value-based purchasing and value-based insurance design, must acknowledge that there is no universal consensus definition as to what constitutes value. To date, the consumer perspective has been underrepresented in discussions of value-based strategies such as pay for performance, capitated and bundled payments, and high-deductible health plans, which have been driven primarily by payers and providers. This article will discuss 3 elements of value from the perspective of families of children and youth with special health care needs: the role of families in the delivery of care, consumer perspectives on what constitutes quality for children and youth with special health care needs, and health care and health care financing literacy, decision-making, and costs. The undervalued contributions made by family members in the delivery and oversight of pediatric care and the importance of partnering with them to achieve the goals of the Triple Aim are stressed. The article closes with a discussion of recommendations for a future policy and research agenda related to advancing the integration of the consumer perspective into value-based purchasing and value-based insurance design.

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Improving health care delivery and ultimately health outcomes while reducing costs is an ambitious goal that requires fundamental reforms in the current system. With the passage of the Affordable Care Act in 2010, the United States continues incremental efforts at reforming the systems of insurance coverage, delivery, and financing of health care. Attention has now turned to deriving greater value from the health care-related dollar under a framework developed by the Institute for Healthcare Improvement (IHI) called the Triple Aim.¹ The Triple Aim includes the following dimensions, which must be pursued concurrently to maximize impact:

- Improving the patient experience of care (including quality and satisfaction);
- Improving the health of populations; and
- Reducing the per capita cost of health care.

The IHI Triple Aim identifies the essential role engaged patients and families have to play in the achievement of these goals, including the need for them to be well-informed stakeholders, on the individual and the system levels.²

An array of strategies to achieve the Triple Aim are being tested across the country under the headings of value-based purchasing (VBP) and value-based insurance design (VBID). A companion article in this issue, “Statement of the Problem: Health Reform, Value-Based Purchasing, Alternative Payment Strategies, and Children and Youth With Special Health Care Needs” (Bachman et al) addresses VBP and VBID strategies, focusing especially on their relevance to children and youth with special health care needs (CYSHCN).³ These strategies conceptualize value as that which “encourages the use of services when the clinical benefits exceed the cost and likewise discourages the use of services when the benefits do

not justify the cost.”² This definition is limited in that it presumes that what constitutes a clinical benefit and its associated risk is uniformly agreed upon by all stakeholders, including patients and families; that the professional prognostication about the clinical benefit of a specific service for a specific patient is accurate; and that all stakeholders have equal access to information and a similar level of agreement about benefit.

The majority of VBP and VBID initiatives to date have been focused on adults with chronic illnesses, rather than on children and notably not on CYSHCN or, by extension, children with medical complexity. Overall spending on children’s health is a small fraction of what is spent on adults,⁴ making the adult focus understandable. However, given the increasingly longer lives CYSHCN are living, this focus may be shortsighted. An emphasis on cost-effectiveness rather than cost reduction might be more appropriate for children’s health, especially for those with special health care needs.

Spending on children’s health is different from that of adults in other important ways. It should be seen as a societal investment rather than simply a cost, in the way that education is, with the benefits accruing over the life course rather than in any 1 enrollment period or fiscal year. The benefits of children, especially CYSHCN, entering adulthood in a healthier state has implications not only for individuals but also for society in general.

The focus in current VBP and VBID strategies on adults raises important questions with regard to applying them to children’s health care coverage, delivery, and payment improvements. How will children’s health needs and care, which are distinct from those of adults, be addressed, delivered, and measured? How will policymakers ensure that the valuable experience and

perspectives of families are included in the development of VBP and VBID strategies, as called for in the IHI Triple Aim? When these strategies are developed with meaningful input from families, especially families of CYSHCN, they promise to lead to care and health plan choices that are more understandable, affordable, and effective, and better health care outcomes based on quality care for children as judged by both their families and health professionals.

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS: AN OVERVIEW

According to the definition used by the federal Maternal and Child Health Bureau, CYSHCN are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁵ This definition is broad by design, encompassing all aspects of health. According to the National Survey of Children With Special Health Care Needs, ~15.1% of the population <18 years old has special health care needs, or 11.2 million children.⁶

Families of CYSHCN experience significant impacts as the result of their child’s health care needs. Almost a quarter of families report >\$1000 in out-of-pocket spending and 13.1% report spending >11 hours a week providing both direct, medically related care and care coordination activities. Noteworthy inequities exist in families reporting they are not partners in shared decision-making, ranging from 25.8% of white families to 36.5% of Hispanic families.⁷ The evidence is clear that reform in the system of care is urgently needed to optimize children’s health and family well-being. The goals of improving quality and reducing costs are critical issues of concern to families and to payers, providers, and policymakers.

FAMILY PERSPECTIVES ON QUALITY

Although there is strong support among payers, providers, and families for the importance of considering quality in making health care decisions, how each of these groups defines quality, and what elements should be included in quality measurement and quality improvement approaches, must be mutually agreed upon. There is recognition of the importance of including the perspective of families in efforts to improve quality, and there has been partnership with families in some efforts to develop quality measures and to undertake quality improvement activities; however, although progress is being made, it is a complex and slow process.

For families of CYSHCN, quality is more than the cost or delivery of a specific kind of health care because for many, the requirements of their child with special health care needs affects every aspect of their family's life. Receiving respect and support for the full extent of the impact of their child's needs on their family as a whole, or markers of quality of life for the family, are a critical part of what is important to a family's understanding of quality. Understanding is essential given the important role consumers play in achieving VBP and VBID objectives. Quality markers important to families may also be broader than those important to providers or payers; for example, they include the number of school days and work days missed and readmissions to the hospital. Work days missed have an important impact on costs to families because they may affect wages and job stability.

Families of CYSHCN undertake extensive efforts to identify, manage, supervise, and in many instances provide high-quality health care for their children. Families develop many clinical skills to care for their child at home: administering medications;

ordering supplies and managing medical and other technology needed by their child; selecting, training, and supervising home care providers; researching diagnoses, specialist providers, and treatments; coordinating and transporting their child to appointments; tracking medical reports, financing options, and payments; researching program options and community services; and coordinating their child's participation, all while managing their own employment, time, and budgets. These efforts by families, which result in significant cost savings, occur in ways that are often invisible or unrecognized by the health care system. This is a primary reason why partnering with families is critical to achieving value; they are inextricably involved, indispensable partners who must be better recognized as such to achieve optimal outcomes.

Measuring quality must occur at multiple levels if we are to effectively improve care, and there are roles for families as partners at every level in these efforts. At the individual level, in addition to VBP measures of clinical care, quality input from families might include opportunities for families to prepare for visits with providers through previsit questionnaires, perhaps through an app or Web site, which would allow a family to identify what is most important to them at that time and allow the family to make more effective use of the appointment. A follow-up questionnaire could offer important information on whether the family has any remaining unanswered questions. A link to a parent mentor or coordinator after an appointment allows the family to ask questions that might have arisen since they met with the provider. Feedback is also critical at the level of the practice. Practice-level surveys could be administered electronically, periodically, to randomly selected families, and cover a more extensive

set of questions and a longer time frame. A family advisory committee focused on quality or overall practice procedures can provide additional authentic feedback for improving services. At the population level, quality measurement should engage family organizations to identify trends they are seeing based on the assistance they provide regularly to families throughout the community.

There are efforts under way to measure quality through health insurance. The Children's Health Insurance Program Reauthorization Act of 2009 required the US Department of Health and Human Services to identify and publish a core measure set of children's health care quality measures for voluntary use by state Medicaid and children's health insurance programs, to be updated each year.⁸ The original core set of children's health measures included the Consumer Assessment of Healthcare and Systems (CAHPS) and a supplement for CYSHCN that includes a set of screening questions and family-reported questions about access to prescription medicines, access to specialized services, coordination of care and services, and access to family-centered care, defined as having a personal doctor or nurse who knows the child, shared decision making, and getting needed information.

The Children's Health Insurance Program Reauthorization Act brought focused federal attention to the need to measure child health quality.⁸ The Agency for Healthcare Research and Quality and the Centers for Medicare & Medicaid Services worked together to implement provisions of the legislation specifically for children served by children's health insurance and Medicaid programs. Their joint activities included 10 grants to support quality initiatives in 18 states, grants to 7 "Centers of Excellence" to develop new quality measures and opportunities for tailored technical assistance

and peer support to expedite knowledge transfer, and a recent grant opportunity to continue implementation of new quality measures. Although Family Voices and other family-led organizations received small stipends and contracts through some of these initiatives, the majority of the funds have gone to universities or state agencies. The research continues. An evaluation has produced examples of impact and lessons learned through these investments.⁹ One impact brief is on peer support for families of CYSHCN as a quality improvement strategy.¹⁰

There is substantive knowledge and experience among families of CYSHCN to contribute to quality improvement efforts. A national network of family-led organizations, called Family-to-Family Health Information Centers (F2F HICs), with family staff knowledgeable about health care quality and financing and the experiences of a broad array of families of CYSHCN, is funded in every state and the District of Columbia by the Health Resources and Services Administration, Maternal and Child Health Bureau, within the US Department of Health and Human Services. Each of these 51 statewide F2F HICs provides direct assistance to families and providers to address health care issues for CYSHCN, and many are active in efforts to improve quality.¹¹ Family Voices, the premier family leadership and advocacy organization focused on the broad population of CYSHCN, provides technical assistance and connections between these F2F HICs, helping to spread family perspective and expertise nationwide, and has been very active in efforts to improve and measure quality.

After helping to organize focus groups for the development of the CAHPS, Family Voices realized that the families they served believed there were many areas important to quality measurement beyond those included in the CAHPS. Family Voices

led a collaborative initiative with providers and researchers to create a set of strongly validated questions that family leaders and individual families believed most important in measuring the implementation of family-centered care.¹² They included questions for families about their comfort in speaking with their child's provider when they disagreed, their provider's respect for family beliefs and practices, including extended family members in decision making, recognizing family strengths, asking about the well-being of the family, assisting with connections to other families, assisting with connections to community services, helping to plan for life changes, providing care in community settings, and providing help with insurance. The questions have been widely requested and used and demonstrate the value of research originating with families themselves. All these elements, individually and collectively, can be considered additional measures of quality and value from the perspective of families of CYSHCN.

Other projects Family Voices has undertaken with families regarding their experiences of care provide more examples of differing perceptions of what is important to measure around quality and include such topics as whether immunizations have been given versus whether a provider has answered a family's questions about the importance of an immunization, hospital readmissions and use of the emergency department versus whether a family has received culturally competent peer support from their provider's office regarding questions on a discharge plan and how to get questions answered when recently released, BMI versus whether a family has had opportunities to discuss with peers their family's access to healthy foods, adherence to developmental screening versus whether a family has had peer support about the

importance and mechanics of follow-up to screening, and use of the electronic health record versus whether a family has access to the electronic health record and understands what it includes.

F2F HICs provide many replicable examples of quality improvement activities that demonstrate the value of partnership with families. An example across systems is a collaborative project of the University of Utah Department of Pediatrics, Title V, and pediatricians and family staff from the Utah F2F HIC, which jointly developed a Medical Home Portal for families, clinicians, and allied health care professionals (www.medicalhomeportal.org/) to ensure that all parties have access to information to enhance comprehensive, coordinated care for CYSHCN. In a collaborative community-level project in West Virginia, the F2F HIC is working with the Title V agency to improve the quality of service delivery related to care coordination and the Medical Home, redesigning state policies and procedures for CYSHCN, assisting with family need assessments, attending home visits, supporting families in clinics, and helping with care plan development.

A quality improvement initiative at the practice level, supported by strong evidence-based cost data, is the Rhode Island Pediatric Primary Care Enhancement Project (housed at the Rhode Island Parent Information Network, the state F2F HIC). This pilot project, funded by the federal Maternal and Child Health Bureau, found that housing trained parents of CYSHCN in pediatric practices reduced the cost of care by 11% to 15%, improved appropriate utilization of health care services including lowering inpatient utilization, and increased both parent and provider knowledge and satisfaction.¹³ The project involved housing trained family resource specialists in primary care practices

for 20 hours a week to provide support to families navigating across and advocating within multiple systems, and to primary care providers on partnering more effectively with families, as well as providing both with information on available resources and supports for families.

Another medical home partnership resource, *The Family Engagement Guide*, was developed by the National Institute for Children's Health Quality in conjunction with Massachusetts Family Voices, the F2F HIC at the Federation for Children With Special Needs. The *Guide* and its companion materials are available in both English and Spanish, and it was designed to help practices "determine if they are ready to work with families as improvement partners, how to recruit and work with Family Health Partners and how to evaluate, sustain and improve the Family Health Partners role and relationship."¹⁴

Work on quality improvement activities from the world of adult health care can also offer lessons that have the potential to inform related efforts in pediatrics. A recent publication analyzed consumer engagement in Accountable Care Organizations in 6 states, combining data from Web site reviews and semistructured, in-depth interviews with consumer advocates.¹⁵

Although Accountable Care Organizations are required to involve consumers, the study found that how this occurs varies. From the interviews, examples and suggestions are cited, such as "being mindful about meeting times and locations; providing adequate time in advance of meetings for consumers and consumer advocates to review materials and provide their input, ensuring that recommendations have impact; and ensuring appropriate support such as funding and training for consumers and consumer advocates." Consumer advocates

also focused on more specific and technical issues such as "the impact of potential payment incentives, the availability of user-friendly enrollment and eligibility processes, full integration of behavioral health services, the availability of long-term services and supports, and improvements to cultural competency and disability sensitivity in care delivery." As the authors note, "There is a need to further assess whether strong consumer engagement structures produce meaningful consumer engagement, and in turn, whether this engagement ultimately results in better health outcomes over time," which is consistent with other literature on family, patient, and stakeholder engagement. It is not enough to have a process or policy in place regarding consumer engagement; it must be operationalized and continuously assessed to be effective.¹⁴

An important aspect of discussion about quality measurement and improvement is the time and resources needed to implement the proposed actions, which are at the heart of VBP and VBID, and the will and resources needed to study the impact of engaging families. Many steps described above require resources. Providers, payers, and families must work together to promote the investment of resources from multiple sources that are needed to ensure that authentic quality improvement can occur.

THE ROLE OF FAMILIES IN HEALTH CARE REFORM EFFORTS: PAST AND PRESENT

In the early 1980s, a family in Iowa experienced first-hand both the benefits of advances in medical technology and the barriers presented by existing Medicaid policy. At that time, children who needed significant technological support such as ventilators were cared for and grew up in hospitals

and institutions. Few families could afford this type of care on their own. Medicaid paid for the necessary skilled nursing care and other supports children reliant on medical technology needed, but only if the care was provided in an institutional setting. The Beckett family, knowing they could safely care for their young daughter Katie at home with the right financial support, challenged this policy, and the Reagan administration made an individual exception (a "waiver") possible for them. When Congress authorized the Home- and Community-Based Service waiver in 1984, states could apply to expand this option to other children and families. It was the tenacity of the Beckett family that broke through this barrier and set the stage for a wave of powerful family advocacy that continues to this day.

The Beckett and other families' efforts in the 1980s and 1990s to move their children assisted by medical technology out of hospital and institutional care and into their homes and communities was seen largely as a financial issue by policymakers and payers but also, more importantly, resulted in the initiative now known as family-centered care. Children on ventilators, cared for in hospital intensive care units by highly skilled professionals, came home to be cared for by community nurses, who needed training and supervision, and by families themselves. Because of the combination of funding gaps and workforce shortages, families and growing children themselves needed to become expert providers and overseers of care, in collaboration with health care providers. In turn, it was obvious that if children with the most significant needs could be cared for at home, so could children with a variety of other, less intense needs.¹⁶ Consumer efforts and reforms, led largely by families and supportive professionals, resulted in the philosophy of family-centered,

community-based care and has become the approach of choice in pediatrics. As stated by the American Academy of Pediatrics, “patient- and family-centered approaches lead to better health outcomes and wiser allocation of resources as well as to greater patient and family satisfaction.”¹⁷

A recent article in *Pediatrics* described the value of peer support in helping families with health coverage, 1 of the few studies documenting the effect of such system-level engagement. In the randomized trial, parent mentors, who were parents of children with particular health conditions and risks, leveraged their relevant experience to help other families with applying for insurance, retaining coverage, identifying medical homes, and addressing social needs, resulting in improved care, reduced costs, increased satisfaction, and improved coverage.¹⁸

Empirical information, a sophisticated network of experienced family leaders, and new ideas about VBP and VBID and its potential impact on families of CYSHCN are available now, even if the terms are not used. Family Voices and the 51 F2F HICs have >25 years of experience as experienced advocates helping families of CYSHCN in every state and providing system-level assistance to families and professionals for health care financing, quality, and related topics. Diagnosis-specific organizations also offer information and respond daily to individual and family questions. A system for collecting and disseminating specific information that provides family perspective and expertise about VBP and VBID is already in place, and it can help shape new approaches to improving the effectiveness of a system of health care for all children, including CYSHCN.

Efforts to increase value, achieve quality, and improve

cost-effectiveness must include the population of CYSHCN. Research should be undertaken now to respond to new questions and approaches and to validate existing impressions and analysis. Value-based purchasing is a current approach to achieving the Triple Aim, but others may arise. The population of CYSHCN is small and diverse but is a vulnerable population in the larger context of overall health care spending. It would be useful to thoughtfully and consciously review information from population groups with whom an affinity is shared, such as the population of all ages who live with disabilities, chronic illnesses, and special health care needs; the population of all children, including those with special health care needs; and older adults. This review might help capture the attention of policymakers for whom CYSHCN are currently “actuarially invisible” and base future policymaking on evidence (either pro or con) for a specific strategy as it relates to CYSHCN.

The continuing, intense focus on health care coverage, delivery, and payment reform has necessitated that families and family-led advocacy organizations continue to take active leadership roles to improve systems of care and protect the interests of a vulnerable population.

CONSUMER CHOICE AND HEALTH CARE FINANCING LITERACY

Until recently Americans have typically had little in the way of choice in private health plans; what an employer offered, if anything, constituted the range of options available to most families. The Affordable Care Act has changed that. As Kathleen Sebelius, former secretary of Health and Human Services, stated during the rollout of the Affordable Care Act, “Exchanges (now State Health Insurance Marketplaces) offer Americans competition, choice, and clout.

Insurance companies will compete for business on a transparent, level playing field, driving down costs, and Exchanges will give individuals . . . a choice of plans to fit their needs.”¹⁹

For many, at least initially, the idea of choice is appealing, and there are many efforts to build in choice and to help consumers make selections. However, families must learn to understand and deal with a complicated and evolving health insurance picture and determine which resources are relevant, timely, trusted, and available when needed. The popular press and academic journals offer insight into the confusion experienced by the general public regarding the selection of a health plan.²⁰

Although theoretically a variety of supports are available to help families select a health plan, many navigators, consumer-assisters, and others responsible for doing so lack adequate knowledge of the complex system serving the needs of CYSHCN and their families. Therefore, the first difficulty may be in selecting the most appropriate support and answering the questions on which choices are predicated. Some questions families are often asked are straightforward, such as the name of the family’s doctor and their hospital of choice; others are more difficult to quantify, such as the cost of an affordable doctor visit, the past year’s health expenditures, and the past year’s out-of-pocket expenses. Although some families may keep records, others do not, and utilization and expenses change from year to year, especially for a child with dynamic health needs.

In 2004, the Institute of Medicine released an influential report on deficits in health literacy and began a series of initiatives to address them. Titled *A Prescription to End Confusion*, it used the definition of health literacy as “the degree to which individuals have the capacity to obtain, process, and understand

basic health information and services needed to make appropriate health decisions.”²¹ It found that only 12% of adults were “proficient” and 36% had “limited” health literacy (50% of those from low-income backgrounds). Other sources reveal the consequences of low health literacy rates, linking them to poor health outcomes, higher rates of hospitalization and emergency department use, less frequent use of preventive services, and higher health care costs.²² These findings are particularly concerning with regard to the goal of increasing value in health care spending. The Institute of Medicine report raises serious questions about the American public’s ability to understand and make the many health and health care financing decisions that are necessary today; for families of CYSHCN or with chronic health conditions, the stakes seem even higher.

A recent review article looked at families of CYSHCN and found very limited studies on their health literacy, most relating to specific conditions such as asthma and none related to health care coverage or financing literacy. Their conclusion: “Parental/caregiver health literacy is an understudied area.”²³

Almost universal access to the Internet has brought previously unimagined kinds and amounts of information to families of CYSHCN, with wide variability in its quality and reliability. Access to the Internet has its benefits, including facilitating families’ connections to professional and family resources and organizations of many kinds at many levels, and importantly, to other families in similar situations, many willing to share information, support, strategies, tips, and resources.²⁴ An article exploring Internet use by families of low-income CYSHCN found that 82% had access. About half of respondents thought they could tell high-quality

from low-quality resources and felt sure about using online information to make health decisions for their children.²⁵ That confidence may be misplaced. A growing body of work raises alarming questions as to the quality and content of online health-related information and the need for increased digital literacy among the general population.^{26,27} Even accurate information is often presented at a reading level that is too high for the average user to understand.²⁸

Health and health care financing literacy and their consequent choices made by families of CYSHCN should be an area of additional research. Insurers and policymakers should be asked, or even required, to take the findings into consideration as information that affects the general public is developed and made available. Plan choice is difficult for any family, but for families raising CYSHCN, decision errors are more likely to result in children not being able to access the care they need and families paying more than they should or even going into debt (a common cause of personal bankruptcy). Seeking to understand and search out answers to questions about coverage takes time and can cause anxiety and frustration. The need for plain language coverage and benefits counseling supports is more essential than ever. The number of CYSHCN is increasing, and many children with complex diagnoses are living longer. Inadequate health coverage that results in deficits in accessing care has both short- and long-term consequences, many of which may resonate throughout a child’s life course.

SHOPPING BLINDFOLDED: CHOICE AND COSTS

Like most people, families of CYSHCN need to carefully consider health care-related costs in the context of what they can afford. However,

it is challenging, if not impossible, for families to precisely determine the costs of present care or of care predicted for the future. Families of CYSHCN experience confusion in their efforts to determine the overall costs of their child’s care, including the price of premiums, copays, deductibles, and uncovered services. Families who experience challenges related to literacy, limited English language proficiency, and other vulnerabilities are especially at risk for problems related to health care decision-making.

Furthermore, cost and quality are not correlated in the present system, even though families may assume they are and make decisions as they would when paying for typical consumer goods, such as a new television set. Recent work in behavioral economics has shown that shopping for health insurance is an unpleasant task, with imperfect information, and many people avoid it if possible, even if they are in a plan that does not meet their needs or a more affordable option is available.²⁹

Noted health economist Uwe Reinhardt has compared using the US health care system to walking into a department store blindfolded and months later being handed a statement that says, “Pay this amount.”³⁰ The titles of popular press articles indicate some of the issues: “Revealing a Health Care Secret: The Price” and “Shopping for Health Care, A Fledgling Craft,” for example. Similarly, professional journal articles describe the volume, complexity, and general unfamiliarity of the experience, as well as a lack of literacy and numeracy skills and “weaknesses in human nature” as significant issues for those trying to make sensible decisions. Many have concluded it is not possible to make rational choices in our present system.^{31–33}

Do families of CYSHCN make choices similar to those of families who have previously been studied?

Unfortunately, without more research specifically focused on their decision-making, it seems necessary to assume that their responses would be similar to those found among the general public with regard to choices relating to cost. And, of course, these families have greater expenses to consider and therefore more risk.

VBP focuses largely on the dimensions of cost, quality, and health outcomes, all of which are central concerns to families of CYSHCN. Many aspects of VBP would seem familiar and be positively received by families of CYSHCN if they knew about them and, perhaps more importantly, if they thought that their children's and families' experiences had been considered in creating the constructs. More than policymakers and payers may realize, families do want health costs to be equitable and reasonable for all stakeholders.

CONCLUSIONS

There is broad agreement that increasing the cost-effectiveness and quality of health care services, thereby achieving greater value, is imperative in response to spiraling costs and poor health outcomes. However, how 1 individual or stakeholder group defines value may not be shared by others. Discussion of value in the context of health care must acknowledge that there is no universal consensus definition as to what constitutes value. To date, the consumer perspective has been underrepresented in discussions of value-based purchasing and value-based insurance design, which have been driven primarily by payers and providers.

Additionally, the critical needs of CYSHCN, their families, and providers have been largely invisible to those tasked with designing, carrying out, and evaluating VBP and VBID strategies. Although effective consumer engagement has a

fundamental role to play in achieving the goals of the IHI Triple Aim, the voices of children and families with regard to how they see value have not yet been heard adequately. Opportunities for policymakers, researchers, and family leaders to come together to address these issues exist, but they will require concentrated, coordinated effort and adequate resources to effectuate meaningful change. The following recommendations are offered as a place to start in raising awareness of this vulnerable population and to stimulate the gathering of the evidence that will be needed for increasing value, in all its forms and for all stakeholders, as coverage, delivery, and payment reforms continue.

Recommendations for Policymakers

1. Identify and prioritize the unique needs and preferences of CYSHCN and their families, including the most underserved families of socioeconomic, ethnic, and cultural diversity, in designing, implementing, and evaluating value-based purchasing and value-based insurance design initiatives.
 - a. Engage the expertise and experience of family leadership organizations, specifically national cross-disability groups such as Family Voices, the state-based F2F HICs, and diagnosis-specific organizations at every level of these activities.
 - b. Refer potential plan enrollees whose children have special health care needs to the F2F HICs for help in making the coverage and cost choices that are best for them.
 - c. Create educational tools and incentives for families raising CYSHCN aimed at increasing their health and health care financing literacy. Better-informed consumers are more

likely to make cost-effective decisions.

- d. Increase price transparency and provide other plain-language decision-making tools to help families make informed coverage and health care utilization decisions. Involve families from a wide variety of backgrounds and health care experiences in the design and implementation of such tools, to assist in ensuring cultural competence.
- e. Integrate clinical nuance into value-based insurance design strategies, with a specific focus on the unique needs of subpopulations of CYSHCN (eg, children with medical complexity, children with mental health needs). Clinical nuance recognizes that health services differ in the amount of health they produce, and their benefits depend on who is receiving the service, who is delivering it, and the setting in which it is delivered.

Recommendations for Researchers

1. Evaluate the current health and health care financing literacy levels of a representative sample of families raising CYSHCN, ensuring that the sample includes full representative diversity of the nation: What do families of CYSHCN know, how do they make decisions, what are the results of those decisions, what gaps could be addressed, and what opportunities could be leveraged in improving choice? What specific supports do populations who experience inequities (eg, based on race or ethnicity, income, functional status) need? Disseminate findings broadly, in the peer-reviewed literature and the popular press, targeting policymakers specifically.
2. Conduct research to identify what families of CYSHCN,

including those of racial, ethnic, and economic diversity, value in terms of quality of life and quality of care. For example, are there palliative care principles (in which the alleviation of suffering in all its forms is the primary goal) that could be used as a framework?

3. Evaluate the results of integrating clinical nuance into value-based insurance design for the care of CYSHCN with regard to costs for all stakeholders, health outcomes, and satisfaction of patients, families, and providers.

Recommendations for Family Leaders

1. Join family leadership networks that are working on these issues to add your individual voice to the collective power of the “family voice.”
2. Take advantage of educational opportunities to increase the health and health care financing literacy of yourself, your colleagues, and the families you serve. Stay informed of current trends in health care financing, including new changes, strategies, and approaches so that your contributions are timely and meaningful.
3. Collaborate with stakeholders to create opportunities for participation by other family leaders, especially those from racially, culturally, and economically diverse groups, in shaping health care systems for CYSHCN, especially with regard to new financing mechanisms.
4. Advocate to ensure that those generating policy and research agendas include families, particularly those from racially, culturally, and economically diverse backgrounds, in the design, implementation, and evaluation of their VBP and VBID projects.

ABBREVIATIONS

CAHPS: Consumer Assessment of Healthcare Providers and Systems
 CYSHCN: children and youth with special health care needs
 F2F HICs: Family-to-Family Health Information Centers
 IHI: Institute for Healthcare Improvement
 VBID: value-based insurance design
 VBP: value-based purchasing

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