The Children's Health Insurance Program Reauthorization Act Quality Measures Initiatives: Moving Forward to Improve Measurement, Care, and Child and Adolescent Outcomes

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ABSTRACT

In 2009, a publicly transparent evidence-informed process responded to the requirement of the Children's Health Insurance Program Reauthorization Act (CHIPRA) legislation to identify an initial core set of recommended children's health care quality measures for voluntary use by Medicaid and the Children's Health Insurance Program, which together cover almost 40 million of America's children and adolescents. Future efforts under CHIPRA will be used to improve and strengthen the initial core set, develop new measures as needed, and post improved core measure sets annually beginning in January 2013.

This supplement aims to make available useful information about issues surrounding the initial core set and key concepts for moving forward toward improvement of children's health care quality measures, children's health care quality, and children's health outcomes. The set of articles in this supplement includes a detailed description of how the identification of a balanced, grounded, and parsimonious core set of children's health care quality measures was accomplished by means of an open, public process combined with an evidence-informed evaluation methodology. Additional articles note that Medicaid and Children's Health Insurance Program (CHIP) officials put a high priority on children's health care quality and desire better measures; that publicly insured children are more likely than privately insured children to experience severe, complex chronic conditions and experience poorer quality in some respects; and that some key CHIPRA topics did not yet have valid, feasible measures (eg, availability of services, duration of enrollment and coverage, most integrated health care settings, and some aspects of family experiences of care).

Key stakeholders and observers provide commentary noting the unprecedented scope and nature of the CHIPRA legislation as well as noting areas in which the nation still needs to move to improve health care quality, including its measurement. These areas include greater engagement of families and health care providers in the quality measurement and improvement enterprises, collaboration across federal agencies, more emphasis on clinical effectiveness research to enhance the validity of children's health care services and quality measures, and a need to maintain an emphasis on children as the nation expands health care coverage and attention to quality for all populations.

This overview also notes areas of future priorities for measure enhancement and development, including inpatient specialty, health outcomes, and a focus on inequity.

We and others contributing to this supplement consider the identification of the initial core set to be a significant initial accomplishment under CHIPRA. With sufficient attention to making the measures feasible for use across Medicaid and CHIP programs, and with technical assistance, voluntary use should be facilitated. However, the initial core set is but one step on the road toward improved quality for children. The identification of future challenges and opportunities for measure enhancement will be helpful in setting and implementing a future pediatric quality research agenda.

KEYWORDS: CHIP; CHIPRA; health care quality; measures; policy

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THE NEED TO improve children's health care quality across all domains (eg, safety, timeliness, effectiveness, equity, efficiency, patient centeredness, care coordination, health care delivery system infrastructure capability) is urgent.[1–3] Children in the United States comprise 26% of the nation's population and account for 1 out of 6 national health expenditure dollars.[4] They receive only 47% of indicated clinical care.[5] Racial, ethnic, and socioeconomic disparities in health care for children persist, as do differences by health insurance status

and source.[6,7] In 2004, 41% of children's health care expenditures were paid by public sources; and 12% came from family out-of-pocket contributions,[4] with lower-income families paying higher shares out of pocket. Health care events during childhood can and do have both short- and long-term implications for the productivity and well-being of children and the nation.[8,9] This supplement to *Academic Pediatrics* addresses the opportunities in the recent passage of the Children's Health Insurance Program Reauthorization Act (CHIPRA) to bring a national focus on children's health care quality measurement and improvement.[10]

CHIPRA provides a compelling architecture for improving children's health care quality and outcomes. The law calls for the identification of an initial core measure set to be used voluntarily to assess the state of children's health care quality across and within state Medicaid and Child Health Insurance Programs (CHIP),[11] reporting of these data to Congress and the public,[12] improvement and strengthening of the initial core measures through grants and contracts, applicability of core measures across all public and private programs, the implementation and evaluation of a variety of health care quality improvement strategies by States,[13] and regular updating of Congress on the state of children's health care quality and outcomes.

Although the need to measure and improve quality in public programs had been addressed previously in legislation,[14] the combination of these areas of quality measurement and improvement in a single piece of national legislation was unprecedented at the time that CHIPRA was signed into law. Soon after, the American Recovery and Revitalization Act (ARRA) included provisions encouraging the use of health information technology to measure and improve quality, collect standardized data on patient demographics, and enhance the evidence base for health care quality.[15] In 2010, the Patient Protection and Affordable Care Act (ACA)[16] expanded quality measurement and improvement provisions similar to those in CHIPRA for adult populations,[17] and added provisions to make measurement and improvement of health care quality for children more feasible.[18–20]

This supplement concentrates on the CHIPRA legislation, focusing in particular on the work used to identify an initial core set of children's health care quality measures[11,21–26] and including the views of key stakeholders concerning the work still ahead to achieve the CHIPRA goals.[13,27–30] Complementary activities under ARRA and ACA are noted when they will help extend the reach of CHIPRA, and additional analytic work is used to help set the stage for identifying additional priorities in children's health care quality measurement. Further, under CHIPRA, the identification of the initial core set of measures for voluntary use by Medicaid and CHIP is just a beginning step toward improving quality measurement and outcomes for children. CHIPRA provides for a Pediatric Quality Measures Program (PQMP) to be established by January 1, 2011.[31] The PQMP will work to improve and strengthen the initial core set, and develop new measures when needed. Topics for improvement and development will be identified by the Department of Health and Human Services (HHS) with input from the public as to priorities.[32] Improved core sets of children's health care quality measures are to be posted annually, beginning January 1, 2013. The rationale for publishing this supplement is to make publicly available useful information about issues surrounding the initial core set, including limitations of the set itself and key concepts for moving forward toward improvement.

THE INITIAL, RECOMMENDED CORE SET OF MEASURES

CHIPRA's requirement for publishing an initial, recommended core set of children's health care quality measures for voluntary use by state Medicaid and CHIP programs and the health plans and health care providers with which they engage presented a challenge in terms of timing and scope. CHIPRA required identification by January 1, 2010, of "the types of measures that, taken together, can be used to estimate the overall national quality of health care for children and to perform comparative analyses of pediatric care quality and racial, ethnic, and socioeconomic disparities in child health and health care for children."[10] The measures were to be evidence-based, understandable, based on measures currently in use, and balanced across health services types and settings, child age groups, and measure types (structure, process and outcomes), according to the legislation.[10] To facilitate voluntary implementation by as many state programs as possible, the director of the Centers for Medicaid and State Operations (CMSO) in the Centers for Medicare & Medicaid Services (CMS) strongly urged that the initial core set be both "parsimonious and grounded," meaning relatively limited in number and otherwise feasible for implementation by states.[33] As shown in Table 1, the initial 24 measures posted for public comment met many, but not all, of these tests. Measures cover clinical quality for preventive and treatment services and family experiences of care across all child age groups. Most of the measures are process of care indicators, consistent with health care quality measurement in general, with only 5 health outcome measures. The measures as a whole address areas where medical costs are high, consequences of poor quality are great, and/or there is substantial variation in performance and/or a high need among racial, ethnic, low-income, and special health care need populations of children.

THE SPECIAL ISSUE

The set of articles in this supplement includes a detailed description of how the identification of a parsimonious set of children's health care quality measures for immediate use was accomplished by a Subcommittee on Children's Healthcare Quality Measures for Medicaid and CHIP of the Agency for Healthcare Research and Quality's (AHRQ) National Advisory Council on Healthcare Research and Quality (SNAC), in close collaboration with the CMS and a specially convened CHIPRA Federal Quality Workgroup. An open public process combined

Table 1. Summary of the Initial, Recommended Core Set's Ability to Address CHIPRA Criteria and Their Relevance to CHIPRA Criteria for Measurement*

	CHIPRA Criteria for Measurement							
			Identification of Disparities					
CHIPRA-Specified Measure Topic	Range of Child Ages	Range of Health Care Delivery Settings and Care Providers	By Race	By Ethnicity	By Socioeconomic Status	By Special Health Care Needs Status (SHCN)	Evidence-Based using Oxford Centre for Evidence-Based Medicine Grade†	Structure, Process, or Outcome
Prevention and health promotion (13 measures)	All	Ambulatory, dental	Low birth weight measure only	Low birth weight measure only	NA	NA	9 with Grade B 2 graded both B and D; 1 graded D; 1 not able to be graded	12 process, 2 outcome
Treatment and management of acute conditions (5 measures)	All	Ambulatory, dental, emergency department (ED), inpatient	NA	NA	NA	NA	2 graded A; 2 graded B; 1 graded D	4 process, 1 outcome
Treatment and management of chronic conditions (4 measures)	All	Ambulatory, ED, mental health care	NA	NA	NA	Inherently SHCN	1 graded B; 1 graded C; 2 graded D	4 process
Family experiences of care (1 measure)	All	Ambulatory	NA	NA	NA	Yes‡	B	Outcome
Availability of services/access	12 mos-19 years	Ambulatory	NA	NA	NA	NA	NA	Outcome
Most integrated health care setting	No measures in the initial core set							
Duration of enrollment								

*CHIPRA = Children's Health Insurance Program Reauthorization Act (Public Law 111-3, February 4, 2009); NA = data to identify disparities are not available based on current use of the measure; SNAC = AHRQ National Advisory Council on Healthcare Research and Quality Subcommittee on Children's Healthcare Quality Measures for Medicaid and CHIP.

†Using the Oxford Centre for Evidence-based Medicine grading system (http://www.cebm.net/?o=1116), available published evidence was reviewed and grades were assigned as follows. Grade A was assigned to a measure topic with consistent level 1 studies. Grade B was assigned to a measure topic with consistent level 2 or 3 studies or extrapolations from level 1 studies. Grade C was assigned to a measure topic with level 4 studies or extrapolations from level 2 or 3 studies. Grade D was assigned to a measure topic with level 5 evidence or troublingly inconsistent or inconclusive studies of any level. See Mangione-Smith and colleagues[11] (this issue) for further explanation of the grading process.

‡The CAHPS Medicaid 4.0 measure of patient experiences of care recommended by the SNAC included the Children With Chronic Care (CCC) items.

with an evidence-informed evaluation methodology identified a balanced, grounded and parsimonious core set of measures that should be feasible to implement on a widespread basis over time.[11]

To provide background information for the SNAC's consideration of the importance of specific measurement topics (within the CHIPRA legislative framework), Bethell was commissioned to analyze data from the 2007 National Survey of Child Health on the prevalence and incidence of childhood chronic conditions, and certain aspects of health care quality. Her article, included in this special issue, finds that an estimated 43% of US children currently have at least 1 of 20 chronic conditions, not including overweight or obesity.[21] Rates and severity of chronic conditions are higher among publicly insured children after controlling for other demographic and socioeconomic factors, and variations across States are substantial. Quality of care varied between children with public versus private insurance on all but 3 measures. Along with data from other sources,[6,7] Bethell's analysis can provide further guidance as measure improvement efforts proceed. Hess and deLone's analysis of recent survey data provides a compelling case that CHIPRA's quality provisions come at an opportune time for State Medicaid and CHIP programs. These programs report that health care quality improvement is relatively high on their list of priorities and that officials desire better quality measures.[23]

Four additional articles commissioned during the process of identifying the initial core set assess the state of the measurement science for several topics identified as priorities for the legislation. Kenney and Pelletier's article addresses measures of duration of enrollment and coverage in Medicaid and CHIP and confirm that having such measures is critical to understanding health care quality within the programs.[24] Currently, over 25% of children are excluded from quality measurement in Medicaid and CHIP because of differing exclusions based on duration of enrollment. In her analysis, Bethell also found an almost 5-fold difference across states in gaps in insurance. Kenney and Pelletier's article identifies several systems-level measures of duration with promising validity based on research studies. However, the SNAC concluded that the measures would need additional testing before being considered feasible in real-world Medicaid and CHIP programs, making this measure topic a high priority for future development. In addition, further development of duration measures is needed for use with specific quality measures.

CHIPRA also identified measures of availability of services as a high priority for the core set. Availability of services for children enrolled in Medicaid has been of concern since the program began; having valid measures of availability would complement current measures of realized access (eg, number of members who had at least one visit with a primary care provider annually[34]; Table 1) given that lack of realized access can have multiple determinants other than whether services actually exist (eg, parental attitudes towards need for care). Kuhlthau's article[25] identifies several measures of availability that can be built upon in the future (eg, geographic accessibility, provider willingness to accept insurance type). However, the article suggests that the subfield of quality measurement development for availability is likely not as far along as that for other topics. For example, only several subspecialties have been subject to measure development, and almost all the work has occurred in a research rather than measure development context.[35]

CHIPRA also called for measures of the "most integrated health care setting" for children. In another article commissioned for use by SNAC, Sternberg and colleagues focused on the medical home as an exemplar of integration and examined the validity and feasibility of measures of "medical homeness."[26] The article recommends several promising approaches to measuring this concept using existing surveys (eg, Consumer Assessment of Healthcare Providers and Systems [CAHPS®] and the National Surveys of Child Health) and structural approaches to measurement (eg, National Committee for Quality Assurance[36]). However, none of the recommended measures had been validated for assessing medical homeness at the time the article was initially prepared. Since then, there has been more attention to assessing relationships between medical homeness and desirable child health outcomes, which could improve the possibility of including a medical home measure in one of the improved core sets.[37–39] In addition, a broader concept of integration, the pediatric accountable care organization, was included in the ACA and will be tested in demonstration projects.[40] Developing and comparing measures of both the medical home and the pediatric accountable care organization could be a high priority for the CHIPRA PQMP.

Although SNAC was able to respond to the CHIPRA call for a measure of family experiences of care by recommending the CAHPS Medicaid 4.0 for children with chronic illness for all children, Co and colleagues point out that work is still needed on measurement of inpatient experiences for children using mental and behavioral health services and of experiences of care at the clinician-group level.[22] Wells and Partridge point out additional concepts for further development and testing within the current family experiences of care measure sets (eg, resolution of differences of opinions between providers and families; direct measurement of need for language interpretation).[30]

Despite the disappointment of not being able to identify several of the measures identified in the CHIPRA framework, several of the commentaries from key stakeholders recognize that the process undertaken in 2009, including the commissioned articles, represented a good beginning toward improved measurement and improved children's health care quality. All commenters point out the need to go beyond mere measurement. Perspectives from Wells and Partridge[30] and from Palfrey and Brei[29] and their colleagues also identified a need to educate both patients and providers about the CHIPRA core set and for HHS to work harder to engage these key stakeholders in both using and improving the measure sets. As Wells and Partridge point out, families and child patients have to be ready to use the data from the core sets to demand better care. Provider and patient engagement is a key focus of

the Pediatric Quality Measurement Program.[41] Palfrey and Brei also note the potential for an evidence-based core set to improve pay-for-performance approaches to pediatric quality improvement. Greene-McIntyre and Caldwell emphasize the need for federal collaboration to avoid introducing multiple measure sets from different agencies.[28] Dougherty and Clancy note the contribution of CHIPRA'S focus on measurement and improvement to the potential for transforming children's health care and health, at the same time suggesting that more work under other umbrellas may be needed to enhance the evidence base for measurement and improvement.[27] Finally, Fairbrother and Simpson make recommendations related to States' needs for infrastructure and technical assistance and to the federal government in the context of new quality and coverage initiatives across the entire US population.[18]

The remainder of this introductory piece focuses on setting priorities for measurement.

PRIORITIES FOR FUTURE MEASUREMENT

Although the core set is a good start, considerable work is still needed to improve the initial core set and to develop evidence-based, feasible measures in areas specified by CHIPRA. Some of the missing topics are addressed in the special issue.[22,24–26] In addition, our and the SNAC's experience during the effort to identify the initial core set using CHIPRA criteria led to identification of additional potential priorities for measure development. Some of these priorities can be accomplished through the PQMP and others may require effort from elsewhere. Certainly, States working under the CHIPRA CMS State Quality Demonstration Projects initiative will make a contribution and have their measures considered for the improved core measure sets. These measures will implicitly reflect State priorities for measure development.

Here we focus on 3 topical areas identified by the SNAC as potential priorities (inpatient and specialty care and health outcomes), on inequities in health, and on methodological issues uncovered during the SNAC process. We note why it may be important to focus on these topics, using standard criteria for assessing importance of a topic for measurement, ie, incidence, prevalence, costs and other burdens to the patient, family, and/or society.

INPATIENT CARE

Children ages 0–17 incurred $89.5 billion in inpatient hospital costs in 2007, over half of which was expected to be paid by public insurance.[42] Although children older than infancy are less likely than adults to be hospitalized, quality of inpatient care can have a significant impact on children's mortality, morbidity, and costs.[43–45]

CHIPRA called for a balanced set of measures across providers and settings. However, the only inpatient quality measure meeting the criteria for validity, feasibility, and importance used by the SNAC for the initial core set was the US Centers for Disease Control and Prevention's (CDC) measure for central-line associated blood stream infection (CLABSI) in pediatric and neonatal intensive care units (PICU and NICU). Measuring CLABSI in PICUs and NICUs is very important because infection puts these most vulnerable children at great risk of death. Further, CLABSI is not inevitable, and evidence-based approaches exist to reducing its incidence and sequelae.[46] Nonetheless, this patient safety measure represents only one facet of inpatient care and covers relatively few children, and more inpatient measures are needed. In order to select from among possible topics to choose priorities within inpatient care, potential measure developers might consider examining leading causes and costs of child hospitalization, for example from the AHRQ Healthcare Cost and Utilization Project (HCUP) databases or the CDC's National Hospital Discharge Survey.[47,48] As shown in Table 2, the most costly inpatient conditions are found in neonates, particularly newborns experiencing health problems. Beyond the neonatal period, the most costly inpatient conditions within the top 25 diagnostic categories are bronchitis and asthma, simple pneumonia and pleurisy, tracheotomy, other cardiothoracic procedures, and craniotomy. Some of these are costly because the number of children admitted is relatively large; others have low admission rates but high costs per admission.

Data on frequency and costs can be complemented by the increasing literature identifying quality problems in inpatient care, such as data on neonatal care quality,[49] variations in the extent to which proven and unproven therapies are used for common conditions (urinary tract infections, asthma, bronchiolitis, and gastroenteritis),[50] and other documented quality problems.[51–53] Investigation into quality problems can also be aided by examining patient and hospital characteristics associated with higher than average mortality or readmission rates. For example, an analysis performed by one of us (DD) of the Kids Inpatient Database using HCUPNet[47] reveals that child inpatient mortality is higher for patients whose likely payer is uninsured, Medicare, or Medicaid than privately insured patients, in large hospitals, and in the South compared to other regions of the country. Differences between public and private insurance may reflect the fact that public sources cover many chronically ill children, but the other differences may point to quality problems that would benefit from more systematic and regular measurement. As noted by Co and colleagues, a child inpatient experience of care measure could address an important domain of quality across all inpatients.

SPECIALTY CARE

Pediatrics is typically thought of as solely a primary care discipline, but a recent analysis found that 20% of children's visits to office-based physicians in the United States are to specialty providers, including obstetrician-gynecologists, medical specialists, and surgical specialists.[54] Not surprisingly, specialist visit rates are more than twice as high for children with a chronic condition or disability (26%) as for children without such conditions or disabilities, but 10% of children without an identified special health care need also visited specialists.[54] Thus, the quality of specialty

Table 2. Top 25 Diagnosis-Related Groups, Children Ages 0–17, Ranked by Aggregate Charges, Medicaid as Expected Payer, and Inpatient Hospital Stays, 2006

Rank	Diagnosis-Related Group	Name	Total No. of Discharges	Aggregate Charges, US$ ("National Bill")*
1	386	Extreme immaturity or respiratory distress syndrome, neonate	41 171	6 138 010 716
2	391	Normal newborn	1 263 747	2 782 436 988
3	387	Prematurity with major problems	35 496	2 245 093 329
4	389	Full term neonate with major problems	82 622	1 951 545 387
5	385	Neonates, died or transferred to another acute care facility	41 365	1 688 920 177
6	98	Bronchitis and asthma age 0–17	154 681	1 440 949 727
7	390	Neonate with other significant problems	264 487	1 280 358 420
8	388	Prematurity without major problems	84 928	1 245 205 194
9	91	Simple pneumonia and pleurisy age 0–17	81 821	904 913 303
10	541	Tracheotomy with mechanical ventilation 96+ hours or principal diagnoses except face, mouth and neck diagnoses with major operating room procedure	1 997	762 413 256
11	108	Other cardiothoracic procedures	5 112	738 387 106
12	3	Craniotomy age 0–17	9 554	665 973 288
13	430	Psychoses	37 209	620 137 318
14	475	Respiratory system diagnosis with ventilator support	6 522	596 182 206
15	184	Esophagitis, gastroenteritis and miscellaneous digestive disorders age 0–17	67 373	573 745 831
16	373	Vaginal delivery without complicating diagnoses	71 167	561 992 475
17	26	Seizure and headache age 0–17	33 493	421 896 475
18	110	Major cardiovascular procedures with CC	2 494	408 694 984
19	298	Nutritional and miscellaneous metabolic disorders age 0–17	47 388	398 306 152
20	279	Cellulitis age 0–17	32 524	314 411 091
21	156	Stomach, esophageal, and duodenal procedures age 0–17	10 250	309 979 344
22	542	Tracheotomy with mechanical ventilation 96+ hours or principal diagnoses except face, mouth and neck diagnoses without major operating room procedure	981	293 736 656
23	431	Childhood mental disorders	14 011	281 696 261
24	422	Viral illness and fever of unknown origin age 0–17	31 702	271 676 224
25	417	Septicemia age 0–17	8 744	266 980 998

Source: Kids Inpatient Database, 2006, HCUPNet analysis, March 21, 2010.

*Aggregate charges or the "national bill" is the sum of all charges for all hospital stays in the United States. When a case was missing information on charges, a value was imputed by taking the mean charges for all discharges of the same Diagnosis-Related Group (DRG) with nonmissing charges. Less than 2% of cases are missing charges in Healthcare Cost and Utilization Project (HCUP) data. Because of how missing charges are imputed, simple calculation of number of discharges × mean charge will not always equal the aggregate charges shown in HCUPNet. For the calculation of charges, if length of stay was over 365 days or total charges were over $5 million, the record was dropped from the Nationwide Inpatient Sample, and if length of stay was missing, total charges were set to missing.

care can have a substantial impact on children's well-being. Although relatively little has been published on the costs of care for rarer conditions, available estimates suggest that cost is another reason for making specialty care an essential target of quality measurement and improvement (Table 3). Efforts to improve quality in selected subspecialty areas[55–59] suggest the breadth and depth of quality problems in specialty care; these efforts can provide building blocks for further progress in measure development for accountability by State programs and nationally. For example, performance measures are being used across cystic fibrosis centers to assess quality.[55] The American College of Surgeons National Surgical Quality Improvement Program recently initiated assessment of pediatric surgical outcomes across multiple institutions, finding a rate of unadjusted complications of from 6.8% to 10.2%.[60] Challenges to identification and development of evidence-based specialty-focused health care quality measures include the paucity of evidence for much of subspecialty care[27] and relatively small numbers of children with specific conditions and receiving specific services.[61]

Health Outcome Measures

Patient health is the ultimate indicator of high quality health care. High-quality infrastructure and care processes are precursors to improved or optimal patient outcomes, such as a healthy full-term birth, age-appropriate body mass index, recovery from acute illness, and ability to live as well as possible with chronic illness.[62] One dissatisfaction with the process to identify an initial core set of measures was the relative paucity of meaningful child health outcome measures to measure health care quality (Table 1). Although some intermediate outcome measures are used to assess quality relatively routinely (eg, HbA1c levels reported in the National Healthcare Quality Reports[42]), few entities hold any organizations responsible for individual or child population health status (eg, number of births to teens,[63] child- and family-rated quality of life). However, proxies such as emergency department and inpatient utilization for conditions considered to be ambulatory care sensitive are used, with 2 included in the initial core set (Table 1). Similarly, patient and family experiences of care are a form of outcome measure shown to be related to health.[22]

Table 3. Selected Costly Conditions Requiring Specialty Care, Prevalence of Condition, Inpatient Costs, Overall Cost of Illness

Care Type	Prevalence of Condition or Annual Rate of Health Care Encounters	Number of Medicaid Inpatient Discharges (% of all Discharges Ages 0–17) and Aggregate Charges,* 2006†	Overall Cost of Illness Estimate
Sickle cell disease	1/500 births to African Americans[78]	13 032 (65.6%) $197 054 913	$11 075 (median annual)[79]
Cystic fibrosis	15 000 children[80]	2 269 (42%) $116 546 547	$43 000/year (mean medical expenditures—private only)[81]
Down syndrome, ages 0–4	1/800 newborns/year[82]	NA	$36 384/year (mean medical expenditures–ages 0–4, privately insured only)[83]
Spina bifida	1/2500 newborns/year[84]	NA	$49 602 (age <1); $15 242 (ages 1–17); mean expenditures—privately insured only)[85]
Autism spectrum disorders (ASDs)	About 1 in 110 8-year old children in multiple areas of the United States have ASDs[86]	NA	$6830 (mean); $3600 (median)/ year—privately insured only-with diagnosis in 2003[87]
Oral-facial cleft palate	NA	NA	$22 642 compared to $3900 for an unaffected child‡ (North Carolina Medicaid 1995–2002[88] data); $36 million in inpatient expenditures, $85 million in inpatient costs, 2006§

*Aggregate charges or the "national bill" is the sum of all charges for all hospital stays in the United States. When a case was missing information on charges, a value was imputed by taking the mean charges for all discharges of the same Diagnosis-Related Group (DRG) with non-missing charges. Less than 2% of cases are missing charges in Healthcare Cost and Utilization Project (HCUP) data. Because of how missing charges are imputed, simple calculation of number of discharges X mean charge will not always equal the aggregate charges shown in HCUP-Net. For the calculation of charges, if length of stay was over 365 days or total charges were over $5 million, the record was dropped from the Nationwide Inpatient Study, and if length of stay was missing, total charges were set to missing.

†Discharges and aggregate costs are for principal diagnoses only, using the CCS codes in the 2006 Kids Inpatient Database (KID).

‡Outcome measures included average cost per child for medical, inpatient, outpatient, dental, well-child care, mental health, and home health.

§HCUPNet analysis using KID 2006, for DRG 52 cleft lip and palate repair, March 13, 2010.

In moving forward to identify or develop more direct health outcome measures relevant to child health care quality, those in the field should be aware of the special challenges inherent in using outcomes to measure health care quality.[64] These challenges are similar to those in adult medicine, although there may be greater opportunities for measuring intermediate markers of disease status in adult than pediatric care (eg, blood pressure, cholesterol). Recent research strongly suggests causal linkages between variations in health care quality and changes in health-related quality of life, some using well-validated measures such as the PedsQL; further investigation and testing of health-related quality of life measures may be warranted under the PQMP.[65–67]

Focus on Inequities in Health

Given the persistence of poorer quality for racial, ethnic and low SES children, and the CHIPRA emphasis on identifying disparities in quality, an additional approach to setting priorities for health care quality measurement development and improvement might focus on known inequities in health. For example, a literature review by Berry and colleagues identified Black children as having higher rates of cerebral palsy and HIV/AIDs, and surviving less often with Down syndrome, type 1 diabetes, and traumatic brain injury when compared with white children.[68] Hispanic children had higher rates of HIV/AIDS and depression, had poorer glycemic control with type 1 diabetes, and survived less often with acute leukemia compared with white children. Black children are exponentially more likely to have sickle cell disease or trait; improvements in the quality of treatment and management of sickle cell enhance the quality of care for Black children overall. Others have written compellingly about the need to address pediatric health disparities.[69–71] Working backward from these differences in health conditions could help identify potential health care quality problems that could then be subject to routine measurement. For example, what might be the role of the health care delivery system in inequities in early deaths from leukemia among Hispanics?[72] Have quality problems been identified for children with sickle cell disease?[73]

Similar strategies might be undertaken for other groups that are likely to be underrepresented for quality measure development, such as adolescents.[74]

Methodological Priorities

Setting priorities for future measurement by clinical topic or setting will not be sufficient to meet the needs of children and the directives of the CHIPRA legislation that measures be applicable across all Medicaid and CHIP program types (eg, managed care, fee-for-service) and able to identify disparities by race, ethnicity, socioeconomic status, and special health care need. The effort to identify initial core measures using CHIPRA requirements identified a number of critical methodological issues for

future measure enhancement and development, including 1) the need for measure specifications that can assess quality across payers, providers, programs, and patient populations, and 2) the need to ensure that data needed to analyze racial, ethnic, socioeconomic, and special health care need disparities are collected in a consistent way (beyond disparities identified by a focus on inequities in health outcomes, as noted above).[75] Meeting a third methodological challenge—to make the best use of emerging health information technologies for quality measurement—is crucial for enhancing the feasibility of the core measures. A fourth is the need to measure the quality of health care services beyond the traditional medical care delivery system (eg, hospitals and physicians/nurse offices) into and across specialized therapeutic services such as mental health, nutrition, physical therapy, and other rehabilitative services (eg, speech). Addressing these issues is likely to be a high priority for the CHIPRA Pediatric Quality Measurement Program (PQMP). Fortunately, the PQMP can build on recent and ongoing efforts in some of these areas (eg, efforts underway to identify racial and ethnic disparities; over a decade of experience with survey-based and other measures to identify children with special health care needs; and use of electronic health records to measure quality).

LIMITATIONS

The work undertaken to identify the initial core set of measures and the approach taken in this overview article to suggest ways to identify priorities has limitations. Limitations of the process to identify initial core measures are addressed in the article by Mangione-Smith and colleagues in this special issue; these were mostly driven by the short time available to complete the process.[11] For example, more time and resources might have improved the extent to which we were able to gather evidence to assess the underlying validity for a greater variety of CHIPRA topics, and to gather information on the range of measures available for consideration by the SNAC. However, in some respects, the short time frame was advantageous because it forced the SNAC to complete the process where previous attempts had struggled.[76]

We have proposed some ideas for setting priorities for future measurement work, but other approaches to setting priorities within children's health and health care may be more fruitful. For example, the NQF relied on Bethell's identification of child chronic conditions in combination with a set of priorities previously established by the National Priorities Project to advise HHS on priorities for future child health care measure development and endorsement.[77] The IOM recently started with a previous IOM framework and the NPP priorities and added to them the areas of access and health systems infrastructure capabilities, but they also suggested a more quantitative and systematic approach as an addendum to their report on the future of quality measurement reporting.[1] Having a standardized and comprehensive approach to priority setting often requires standardized and comprehensive data across a number of domains, a situation that rarely exists. One advantage that CHIPRA provides the child health field is the opportunity to set priorities within child health alone. In many approaches to priority setting, children may be disadvantaged relative to adults or subsets of adults because they comprise only a quarter of the population, incur lower health care expenditures and are less likely as a group to experience costly chronic conditions.

CONCLUSION

We consider the identification of the core set to be a significant initial accomplishment under CHIPRA. Valid, feasible, and important measures for most legislative topics were identified. With sufficient attention to making the measures feasible for use across Medicaid and CHIP programs, and with technical assistance, voluntary use should be facilitated. This achievement builds on the efforts of many who have toiled in the children's health care quality measurement and improvement fields for decades. However, the initial core set is but one step on the road toward improved quality for children. The identification of future challenges and opportunities for measure enhancement was a side benefit of the CHIPRA core measure identification process and has been helpful in setting a future pediatric quality research agenda.

Improving children's health care for the benefit of children's and adolescents' health and well-being has both short- and long-term implications for the children, their families, and society at large. Although quality measurement is not enough, achieving improvement in children's health is inextricably linked to measurement of the quality of health care that is delivered. Commentaries in this supplement provide additional detail on how critical it is to go beyond measurement to continuous quality improvement.[13,18] We are fortunate as a nation that cares for its children that CHIPRA provides a road map for linking future pediatric quality measurement and improvement efforts.

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