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Accelerating Innovative and Effective Pediatric Health Care Delivery Systems:

Interventions and Value-Based Care Models for Children with Chronic Health Conditions and Complex Needs

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Key Points

- Children, youth, and families have unique health needs, which set the foundation for health across the life course; chronic conditions now affect nearly one in three U.S. children, with disproportionate prevalence in those enrolled in Medicaid and CHIP.
- Pediatric care delivery and financing interventions can address system fragmentation and unmet needs to improve health outcomes for children, youth, and families.
    - Strategic improvements in care access; child and family support; patient-centered planning; comprehensive medication management; cross-sector care coordination; connection to services addressing health drivers; and support for transitions of care are key, though evidence remains limited by inconsistent methodologies and a lack of standardized, child-specific outcome measures.
    - Consistent, relevant, quality measurement across the health care continuum and outcomes, while challenging, is critical to advance care quality, support payment, and ultimately improve health.
    - Value-based payment approaches, including accountability for total cost of care and quality outcomes, have the potential to improve outcomes and health care delivery while reducing costs. Value-based payment requires appropriate operationalization and testing that accounts for the unique pediatric landscape.
- The newly announced CMS Innovation Center Accelerating State Pediatric Innovation Readiness and Effectiveness (ASPIRE) Model presents an opportunity for states to improve care and address key issues highlighted in this brief for children who have or are at risk of developing complex health needs.

Introduction

The pediatric years are tremendously important for health promotion, disease prevention and management, and building resilience necessary for lifelong health. Efforts to improve care quality, health outcomes, and health care efficiency are critical for children and youth who face unique challenges due to their distinct needs and developmental trajectories. Long-term investment in prevention and cross-sector approaches are often needed. To measure progress, metrics for pediatric care delivery should be child-specific and reflective of their unique developmental situation, caregiver influence on health, and outcomes that often present years later in their life course. Focused attention on children and youth can provide the benefit of improved child health now and into the future.

Value-based payment models seek to shift provider incentives from volume to quality by tying reimbursement to performance on quality of care and health outcome measures. While evidence is growing, gaps remain with opportunities for testing innovative models of care that meet the needs of children, youth and families who face high and rising risks from chronic conditions and complex situations. This brief is intended to be a resource for provider groups, policymakers, the health services research community, and other partners designing new approaches or services for improving health outcomes in children and youth covered by Medicaid and the Children's Health Insurance Program (CHIP).

Pediatric Chronic Conditions: Putting the Health of U.S. Children and Youth at Risk

The prevalence of pediatric chronic conditions in the U.S. has risen to just over 30% [1, 2], increasing annually by approximately 130,000 additional 5- to 17-year-old children per year from 1999/2000 to 2017/2018 [1]. From 2011 to 2023, the prevalence of 3- to 17-year-old children with a chronic condition rose from 25.8% to 31.0% [2]. Of the chronic conditions and functional limitations in children, respiratory and behavioral conditions are the most frequent in the population [1]. Common examples of pediatric chronic conditions include asthma, diabetes, autism spectrum disorder, and anxiety. Additional examples such as cerebral palsy, cystic fibrosis, and sickle cell disease can significantly affect children across their life course.

The definition and impacts of pediatric health conditions can encompass the diseases or conditions themselves, and effectively managing chronic conditions in children and youth requires also addressing the upstream drivers of health and situations that also put children at risk of long-term adverse health outcomes. Children and youth with special health care needs (CYSHCN) have been described as those who have or are at increased risk for having chronic physical, developmental, behavioral, or emotional conditions; they may require more specialized health and educational services to thrive [3]. Other definitions of health status focus on limitations imposed on routine activities of daily life. Disability is any condition of the body or mind that makes it more difficult for the person to do certain activities and interact with the world around them [4]. Moreover, children may be in situations that put them particularly at risk of long-term adverse health outcomes such as youth who are institutionalized or in foster care. In the population of children on Medicaid, those receiving home and community-based services waivers and those involved in the child welfare system can indicate a higher level of complexity and need.

Pediatric chronic health conditions and upstream drivers of health can require ongoing care and affect a child's quality of life. This can also put children and youth at high and rising risk of long-term adverse outcomes. Chronic conditions may disrupt a child's life and development, in part through challenges such as peer harassment and school absenteeism [5]. Disrupted routines, lifestyle adjustments, medical demands of the condition, emotional and social challenges can lead to ongoing stress, negatively affect mental well-being and daily functioning for both children and families [5]. Children with chronic conditions face a significantly higher risk of developing comorbid mental health disorders. They are about twice as likely to have a psychiatric illness at ages 10 and 13 years compared to children without chronic conditions, and have a 60% higher rate of poor mental health outcomes at age 15 years [5]. Overall the physical, behavioral, and social needs of children and youth can place them at high or rising risk of poor health outcomes, facing care gaps and delays, unmet needs, high utilization of services and costs, and continued need of services into adulthood.

Pediatric Care Delivery Interventions

Pediatric care delivery interventions based on effective strategies across the health care delivery system and continuum of care are needed to meet the needs of children and families dealing with chronic conditions and situations that put them at high and rising risk of poor health outcomes.

Health Care that Meets the Needs of Patients

It is critically important to focus efforts on addressing the needs of children, youth, and their families across their health care journey over their life course. Traditionally improvements have focused on coverage, timeliness, and capability of the individual service itself [6, 3]. New care models can be reimagined as a proactive, human-centered system to address the health care system fragmentation and unmet needs experienced by patients [6]. This section will describe high-impact wraparound services and supports designed around the needs of the child and family. These care delivery interventions have been shown to improve care for children and youth regardless of diagnosis or condition severity by ensuring care is more accessible, family-centered, comprehensive, and coordinated.

(1) Access to Care

Pediatric care can be accessed via suitable mechanisms, settings, and approaches to address unmet needs and empower children, youth and families. For example, telehealth visits have proven helpful in reaching patients where they are at home or in the community [6] and to meet behavioral health needs of patients where there are severe provider shortages [7]. Furthermore, care and consultation can be made accessible when families are available [6], such as through a 24-hour advice call line staffed by a health care professional.

A literature review on children with complex medical conditions found that programs with twenty-four hours a day, seven days a week access to a known provider and/or next day appointments are the most consistent elements for successful intervention [8]. Given the mounting evidence for this expedited access to their care team, future interventions and testing may include further exploration of feasibility, acceptability, and a user-centered design approach for these outpatient programmatic interventions [8].

(2) Child and Family Support

Adequate child, youth and family support is needed to help individuals and family caregivers face challenges and ensure the delivery of high-value care [9]. Oftentimes, pediatric care needs rely heavily on informal and unpaid care of parents or caregivers. Meanwhile, caregivers' quality of life and overall health may be negatively affected as they face increased stress, and decreased sleep, income, employment, and energy. The pediatric care delivery system may offer supports such as in-home care, respite, financial resources, and quality adult health care access [10].

Moreover, support can include connecting youth and family with their peers. Peer support interventions have been delivered through group peer support, remote, community-based settings, and/or integrated within the health care setting where families frequent; this has enhanced the health care team's ability to provide family-centered emotional and tangible support for pediatric patients with complex health care needs [11]. For children with intellectual and developmental disabilities, a literature review identified that peer support networks can strengthen family caregivers, as they share similar experiences and provide critical information to each other, developing resilience and social connectedness [12]. Additional studies can further evaluate the outcomes and effectiveness of peer support networks [11, 12].

(3) Patient-Centered Planning

Empowering families with patient-centered care where children, youth, and families are partners in their health can also improve their experiences of care and outcomes. A comprehensive care plan that synthesizes a patient's medical, functional, and psychosocial needs into actionable steps should be developed with goals that are established with the child's and the caregiver's input when available and applicable. Interventions can include improving communications and providing comprehensive education on topics that support health at home.

Through the interactive process of shared decision-making, patients, families, and providers participate in all phases of the decision-making process and together arrive at a treatment plan to be implemented [13]. This is helpful to align the child's/family's values, priorities, and understanding of perceived best choices and those of the clinician. Tools and resources have been constructed and made available, such as decision aids designed to provide education; outline treatment options, risks, and benefits; and support families' values and priorities [13]. Incorporating voices of all stakeholders, especially in complex decision-making such as faced by children with disabilities and their families, can ultimately support the clinician, the family, and the autonomy and well-being of the child [13].

(4) Comprehensive Medication Management

Comprehensive medication management (CMM) can include all services and interventions related to prescribing, supervising, administering, checking and interpreting labs, monitoring for side effects, and/or providing self-management information for medicines. Provision of CMM can mitigate high rates of medication errors, reduce medication complexity, and benefit children with complex medical conditions. For example, one successful CMM intervention created a clinical pharmacotherapy practice in a pediatric long-term care facility with standard operating procedures to guide CMM, and a collaborative practice agreement to guide drug therapy [14]. This identified, prevented, or resolved drug therapy problems, decreased the average number of medications per patient, and prevented hospital readmissions and unnecessary medical visits for children with medical complexity.

CMM services have been implemented in many, if not all, of the states, yet most published literature does not yet reflect a broader view of the patient's life situation and its relationship to pharmacotherapy and the ways in which the pharmacist implements holistic elements (e.g. tailored interventions based on the context of patient's daily life, exercise, and dietary habits) to solve or prevent drug-related problems [15]. This leaves opportunities for further implementation of a holistic approach to CMM that takes into account the physical, mental and emotional well-being of youth, as well as their socioeconomic circumstances; and improving the medication experiences and the pharmacotherapy outcomes from the patient's perspective.

(5) Cross-Sector Care Coordination

Coordination of services and interventions across care sectors and transitions is similarly important to meet the needs of patients. This includes care management and coordination as patients navigate across providers such as specialty care and supportive services and among settings such as the child's school and communities. This can proactively address issues and prevent fragmentation of services with a family-centered, team-based collaboration, bridging physical and mental health care, early intervention, and education to address interrelated needs. Goals include seamless care across systems, increased efficiencies, and supported families for improved satisfaction and improved health outcomes.

Dedicated care coordination, as a team-driven activity that organizes and drives service integration, is increasingly seen as key to addressing the fragmented care that children with complex medical conditions often encounter [16]. For Medicaid-enrolled children with disabilities, caregivers who had a care coordinator helping with specialist appointments or advocating for children reported higher satisfaction [17]. While caregivers report high-quality care coordination improves quality of life, there is further opportunity to provide tools and assess approaches to accomplish the goals of cross-sector care coordination.

Furthermore, interventions that are cross-sector through the settings children live, learn and play, and multi-level across the socioecological model have been used to address chronic conditions. One such model delivered multi-sector, multi-level supports with care coordination by community health care workers to improve care and outcomes for children in sites across the U.S. on Medicaid and CHIP who were overweight or obese [18]. Appropriate resource allocation under new payment models could help with further testing and implementation of effective multi-sector care coordination [16].

(6) Connection to Services Addressing Risk Factors

Cross-sector interventions for children and youth needs must include connection to services that address risk factors and well-being. Pediatric care integrates preventive services like nutrition counseling and mental health screenings into routine visits to improve long-term health. Supportive services can, for example, address lack of knowledge and resources to engage in optimal levels of physical activity or improve consumption of healthy foods. Also critical is building resiliency and addressing food, housing, child care, and education necessary for well-being and quality of life [19]. Addressing these needs can improve intervention effectiveness and reduce disparities in childhood chronic conditions, such as obesity [20].

Children and youth, especially those with increased medical complexity, can have elevated risks that often require additional nonclinical supports to thrive, such as supportive housing, food assistance, and special education, yet the current system is not ensuring access to these services [21]. Sectors, systems, and programs should be designed and implemented to mitigate these health effects on children and youth [21]. To decrease barriers to service connection, some supportive services programs co-locate with health providers onsite to provide fee-free care rather than requiring youth to seek medical care through a separate system thus streamlining redundant intake and case management [22].

(7) Support for Transitions of Care

Youth and families should be supported across care transitions that may cause challenges and affect care quality and outcomes. This includes appropriate follow-up from inpatient hospitalization to other settings post-discharge. This can also include proper continuity of care as patients encounter changes in service providers, their own life experiences and skillsets across the life stages as they transition from pediatric to adult health care, work and independence.

Families and care teams must be prepared to adequately manage care at home for a safe transition when discharged from the hospital, especially when caring for children with medical complexity. Discharge interventions to support a comprehensive and safe discharge can help improve experiences and smooth the transition from hospital to home. Approaches and strategies include optimal communication with families and community health care providers, relationships that build trust and confidence, and a team approach to planning (e.g., expert support for navigation, parent engagement in follow-up options such as telemedicine, and community care needs such as medical equipment ordered early [23].)

Furthermore, comprehensive care to support and empower adolescents as they shift from pediatric to adult care and transition into adulthood starts early and involves a structured, phased process. It can focus on self-management skills using tools like readiness assessments; address mental, social, educational, and vocational needs alongside medical care; build trust with new providers; and leverage national resources [24, 25]. Youth, especially those with complex conditions and high health risks, can face challenges in accessing age-appropriate care, managing developmental needs and bridging supports for optimal health as their multidisciplinary care is transitioned. Those provided structured transitions have improved use of services, health outcomes, and care experiences [26]. The negative consequences of failed care can be life-altering, and more rigorous studies to guide interventions and systems improvements for transition support have been identified as priorities [27, 28, 29].

Additional Components Key for Success

The adoption of information technology (IT) has the potential to significantly impact pediatric health care delivery. It may create unprecedented access to real-time data that can be used to support decision-making. Despite all the untapped benefits of such technology, its full adoption faces many obstacles. This section will address the IT infrastructure needed, potential for learning health systems, and facilitators for the successful implementation.

Information Technology Infrastructure

To leverage the benefits of IT in pediatric care delivery, strong and reliable IT infrastructure is usually required [30]. Care platforms like virtual care and telehealth can contribute to expanding access to services and improving scheduling [31]. Such platforms played a major role in pediatric care by reducing barriers related to transportation, travel time and parental scheduling [32]. Additionally, they facilitate access to specialty care, especially for children with chronic and high-risk conditions, and for behavioral health services [33]. Much of this innovation is primarily focused on commercial clients, leaving an opportunity to bring this innovation to children with Medicaid coverage.

Information technology plays a vital role in supporting children with complex health conditions and social risks by bridging fragmented systems and empowering families [34]. For example, integrated care coordination platforms, telehealth services, and electronic health records (EHRs) connect health providers, schools, social workers, and families, reducing caregivers' burden while ensuring coordinated care [16]. Additionally, in some cases, predictive analytics can help identify high-risk children early, enabling proactive interventions and better resource allocation [35]. Assistive technologies, ranging from augmentative and alternative communication (AAC) devices and family-centered apps, further support children's communication and learning while helping families manage appointments, track symptoms, and access critical resources. Mobile health applications and web-based tools support family engagement by providing accessible health education, medication reminders, appointment scheduling, and social service navigation. Despite these benefits, several challenges remain including overcoming data silos across sectors, ensuring digital accessibility, and building rigorous research evidence.

In addition to access, IT also creates unprecedented opportunities for tracking care quality metrics while identifying potential gaps in pediatric care delivery by generating data and information needed for decision-making. The systematic collection and analysis of digital health data can help identify patterns in pediatric care delivery and outcomes that were previously invisible, enabling more targeted quality improvement efforts [36].

However, several barriers, such as a lack of capital investment required for IT infrastructure, limited internet access, and low digital literacy, could hinder the full realization of technology's potential [37]. Furthermore, security and privacy concerns are becoming more relevant in pediatric practice, where data protection should address not only parents but also evolving adolescent autonomy. In addition to the technical aspect, reimbursement policy models have historically lagged technological advancement and capabilities. However, recent policy changes and initiatives show promise in addressing the gap [38].

Learning Health Systems (LHS)

The Institute of Medicine (IOM) defines learning health systems as "*one in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience* [39]." They represent a major shift toward continuous, data-driven improvement in pediatric care by systematically capturing insights from every patient encounter and translating evidence into practice. Collaboration and knowledge sharing form the core of learning health systems, enabling providers across different settings to learn from one another's success and challenges. Such an approach becomes even more relevant in sharing information and best practice regarding pediatrics patients with rare diseases [40].

Several learning systems, such as PEDSnet [40, 41] and the Pediatric Research in Inpatient Setting (PRIS) Network [42], have demonstrated that collective learning and knowledge sharing could foster improvement beyond what individual institutions could accomplish on their own. Through pre-existing resources and strong collaboration, PEDSnet has improved health outcomes for diseases such as cystic fibrosis and many childhood cancers [40]. However, the implementation of LHS faces various challenges including cultural resistance to changes among health care professionals, data quality and interoperability, and ethical considerations regarding informed consent [43, 44]. Furthermore, the technical complexity of integrating data from different electronic health record systems creates interoperability challenges that require significant resources which many practices may not possess.

Success Factors

Overall, successful technology adoption and learning systems implementation would require leadership commitment at organizational and policy levels to provide essential resources and remove institutional barriers [45]. Additionally, investment in training and support helps overcome digital literacy gaps among both providers and families. The development and adoption of data standards and definitions would enhance interoperability and data exchange. Finally, incentives structures, such as value-based payment models and patient-centered quality metrics, could facilitate sustained investment in these approaches.

Evidence Across Select Pediatric Conditions

Children with special health care needs covered by Medicaid are more likely to experience physical health conditions, behavioral health conditions, intellectual and developmental disabilities (ID/DD), and multiple chronic conditions compared to children with special health care needs covered by private insurance [46]. Although these conditions frequently overlap, they differ in clinical complexity, service needs, and system-level barriers to care. These differences have important implications for the design and evaluation of health care delivery interventions. Accordingly, this section synthesizes the evidence on effectiveness of pediatric care delivery across major conditional domains among children and youth with medical, behavioral, and social risks associated with suboptimal care experiences, quality, and utilization. Select condition categories below (i.e. CYSHCN, MBDD, and foster care) highlight how health care delivery strategies for example medical, behavioral and social conditions (which are overlapping and not mutually exclusive) can lead to improvements for children and families living with chronic conditions.

Children and Youth with Special Health Care Needs (CYSHCN)

Currently, 26.2% of U.S. children have special health care needs and only 13.0% of these children receive care in a well-organized health care system [47]. Given their elevated risk for chronic and comorbid physical, developmental, behavioral, or emotional conditions, CYSHCN and their families frequently interact with a complex network of providers and public or private programs [48], making coordination difficult and time-consuming [49].

Given the complexity and fragmentation of services, interest has expanded in health care delivery interventions. For example, The National Academy for State Health Policy developed the National Care Coordination Standards for CYSHCN that outlined six key domains for effective care coordination: continuous screening, identification, and assessment; shared care planning and accountability structures grounded in family priorities; timely, effective, and respectful team communication; child and family empowerment and skill-building; a well-prepared care coordination workforce; and support for transitions from pediatric to adult care [50].

Interventions for care coordination vary in the literature ranging from 24-hour access to a care coordinator and development of comprehensive care plans to outpatient visit coordination, facilitated and direct connection between inpatient and primary care providers, and supports across home, clinic, and school settings [51]. Outcomes are equally varied including inpatient and emergency department use, cost of care, caregiver quality of life, satisfaction with the health care system, school absences, and caregiver self-efficacy [51]. The absence of standardized outcome measures limits cross-study comparison and the ability to evaluate effectiveness in systematic reviews. Despite these challenges, there have been multiple systematic reviews that have examined the current evidence base. For example, a review of coordinated care models for CYSHCN identified 14 randomized controlled trials examining care planning, case management, and other approaches such as the medical home model, disease-specific care, and managed clinical networks. The review found modest but not statistically significant improvements in children's health, functioning, and quality of life, as well as a positive but non-significant trend in lowering hospital utilization and costs [52]. Similar findings were observed in transition-of-care interventions for adolescents, which demonstrated small gains in disease knowledge and readiness for self-management but no effects on health status, quality of life, or rates of transfer to adult services [53]. Evidence is also limited for children with medical complexity (CMC), a small but important subset of CYSHCN defined as those with multiple chronic conditions, functional limitations, and high medical and service needs. A review of four randomized controlled trials evaluating comprehensive care programs for CMC found no effect on health, functioning, quality of life, or overall health care costs [54].

For caregivers of CYSHCN, a meta-analysis of case management interventions found small but consistent improvements in mental health, reduced psychological distress, and higher satisfaction with care, though risks of bias limited generalizability [55]. Some reviews similarly conclude that high-quality care coordination improves caregiver quality of life even when effects on children are inconsistent [51], while others report no significant impact on caregiver health or well-being [52, 54]. Additional, a review found that parents valued peer support programs and appreciate the additional emotional support, but studies found no significant effects on parents' psychological distress, confidence, self-efficacy, coping, or quality of life [56].

Children with Mental, Behavioral, or Developmental Disorders (MBDD)

In 2021, 27.7% of children had been diagnosed with a mental, behavioral, or developmental disorder (MBDD). Families of children with MBDD report poorer mental health and more economic strain than those without an affected child [57], yet only 60% of these children received mental or developmental services in the previous 12 months [57]. One contributing factor is the nationwide shortage of mental health professionals, a challenge that is particularly acute for youth and for families living in rural areas [58].

Integrated medical–behavioral primary care models show promise in addressing care gaps. A meta-analysis of 30 studies identified small but statistically significant benefits for mental health outcomes, especially within collaborative care models that use team-based approaches involving primary care providers, care managers, and mental health specialists compared to usual care [59]. A more recent meta-analysis aligned with these findings, reporting that integrated care was superior to usual care across outcome types, with small to medium effects for behavior change, quality of life, and symptom reduction, although not for health [60]. Wraparound services are another option; among children with serious emotional disorders, a meta-analysis found that these services improved school functioning and yielded small positive effects on mental health and overall functioning [61].

Children with Intellectual and Developmental Disabilities (ID/DD)

An important set of conditions causing physical, mental, and social impairments are intellectual and developmental disabilities (ID/DD), affecting approximately 5.3 million children in the United States [62]. ID/DD include, but are not limited to, conditions such as learning disabilities, autism spectrum disorder, cerebral palsy, and fetal alcohol syndrome [63]. These conditions often require additional medical, educational, and social services, although the type and intensity of supports vary widely depending on the specific condition and severity [64]. Evidence supports the use of family-centered care for children with ID/DD, an approach grounded in shared and informed decision-making, ongoing care planning, alignment of services with family needs and values, connection to resources, and a focus on outcomes that matter to families [65]. A systematic review found family-centered care led to improvements in children's behavioral, social, and school outcomes and higher family satisfaction with health services, as well as some evidence of reduced parent stress and increased resilience [66].

Children in Foster Care

One population with elevated situational risk, and a notable pediatric population in Medicaid, are children and youth in foster care. Children and youth in foster care experience higher rates of chronic and behavioral health conditions compared to children who have never been in foster care [67]. As a population considered to have special health care needs, children and youth in foster care often must navigate complex service systems, frequently with incomplete medical histories and limited access to prior health information [68]. In addition, the majority have experienced significant adverse childhood experiences, which are associated with poorer physical, mental, and social outcomes [69] and underscore the need for supportive care [68, 70].

Similar to the broader discussion on integrating primary care and mental health services, care coordination and integrated care are particularly important for children and youth in foster care. Research suggests that coordinated care can improve mental health outcomes, reduce behavioral problems and caregiver stress, and improve outcomes for conditions such as ADHD and depression [70, 71, 72]. Despite this promise, there remains a significant gap in high-quality, longitudinal research evaluating integrated care models within the foster care population, and implementation of these models has proven challenging.

For children and youth with particularly complex needs, therapeutic foster care (TFC) provides services in a family-based setting rather than institutional or group care [73]. TFC typically includes coordinated, individualized treatment planning; specialized training for foster parents; crisis support; structured activities to develop social and coping skills; and access to behavioral health services [73]. A meta-analysis found evidence that TFC, particularly two evidence-based models, Treatment Foster Care Oregon (TFCO) and Together Facing the Challenge, improves social, mental, and behavioral outcomes.

Methodological Limitations Across Populations

All the reviews and meta-analyses highlighted that most of the current studies on pediatric health care delivery interventions are limited by lower quality with medium to high risk of bias, largely due to the lack of standardized clinical and patient-centered outcomes and inconsistent methodologies [52, 74]. Efforts to improve the standardization of valid outcome measures for the pediatric high-risk populations, along with high-quality randomized designs, are necessary to adequately assess the impact of care coordination interventions across pediatric populations with health care needs.

Gaps in Meeting Pediatric Care Needs and Opportunities Ahead

Efforts are ongoing to improve pediatric care, yet gaps persist. In the 2022-2023 National Survey of Children's Health [75], less than half of respondents (45.3%) reported that their child received coordinated, ongoing, comprehensive care within a medical home. One-third (33.5%) of respondents indicated that they did not receive needed care coordination; and 14% did not often feel partnered in shared decision making for the child’s health. Rates were worse among those with higher medical and social needs.

While evidence and progress are building as noted in the sections above, opportunities are critical to address across strategies and conditions for improvements in pediatric care delivery. Enabling better care for children is advantageous now and in the future with improved quality of life, health outcomes, health care utilization, caregiver and family health status, and potential youth long-term benefits such as productivity and health outcomes in adulthood. Cost and payment issues will also need to be addressed for viable implementation of strategies that hold promise in improving care for children and families.

Measurement of Health Care and Health Outcomes

Measurement in care delivery is critical for evidence, tracking, and quality improvement. However, no consistent national standard exists regarding what care outcomes best match with primary care quality [76]. Specifically, for complex pediatric populations, it remains difficult to attribute health outcomes when multiple systems are involved. Existing pediatric quality measures do not reflect important aspects of care for high-risk children and youth, and it is difficult to know how these youth fare compared to other groups due to poor data sharing across medical, behavioral health, and social service systems. This section will explore metrics considerations across the health care continuum and outcomes.

Measurement Considerations for Health Care

A wide variety of quality measures are available for pediatric populations, including those from CMS, Batelle, the National Quality Forum (NQF), and the National Committee for Quality Assurance (NCQA) [77]. The Core Set of Children’s Health Care Quality measures are a set of measures updated by CMS annually. These standardized sets of measures allow states to measure health care quality provided to CHIP recipients [76]. Reporting these measures became mandatory for states in 2024; however, since these measures are completed at the state level, it can be difficult to understand health outcomes at the beneficiary level, [76] and specifically in children with medical, behavioral, and social risks. The CMS consensus-based entity, whose role it is to promote consensus-based recommendations, endorses quality metrics from a variety of sources, creating potential for a wide variety of measures and sources for similar metrics [78]. More granular data would be helpful to better understand factors impacting a beneficiary’s experience, which are available in validated quality measures sets. The Agency for Healthcare Research and Quality (AHRQ) and NCQA offer these validated measures for use in clinical practice [79, 80]. These quality measures may be used to get a picture of the quality of care provided to children and caregiver burden.

The American Academy of Pediatrics (AAP) and several studies noted gaps, specifically for children and adolescents with multiple chronic conditions, since coordinating care across sites can be difficult, along with the limited electronic health record connections between facilities [81, 82, 83]. The AAP suggests that youth with chronic medical conditions face additional challenges. Multiple biological, behavioral, social and physical environment factors impact the health of adolescents [84]. The Healthcare Effectiveness Data and Information

Set (HEDIS) from the NCQA offers opportunities to supplement the Core Set of Children's Health Care Quality measures from CMS to measure quality of care [76, 84]. However, the United States Preventive Services Task Force (USPSTF) recommended services do not align with either the HEDIS or state measures, suggesting an opportunity for CMS to align quality frameworks to close this gap. By closing this gap, consistent implementation of these and other measures across health care settings can eliminate existing challenges [85]. Providing comprehensive care assessments for youth and adolescents that are aligned across governing bodies is critical to achieving optimal care at reduced costs to promote positive health outcomes [84].

Measurement Considerations for Health Outcomes

AHRQ offers several outcome measures that reflect the impact of interventions on the health outcomes of patients. However, factors outside a health care organization or provider's control can impact how an intervention or service affects health outcomes [86]. The AAP suggests that utilizing quality metrics to measure health outcomes may be difficult, due to the complexity of evaluating interventions in multi-payer, layered systems [84]. To help understand health outcomes in pediatric patients with chronic conditions or specialized needs, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Item Set for Children with Chronic Conditions can be used to compare to the general pediatric population. This measures access to prescription medicines, specialized services, family-centered care, and care coordination at the individual beneficiary level [79]. This can help providers better understand the needs of patients and how these may impact providers.

Well-care and well-child visits offer opportunities to check in with pediatric patients to ensure developmental milestones are met. Finnell et al. noted that the AAP Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents offer over 2,000 action items for consideration; the team consolidated these action items into 245 recommendations with 52 of them being actionable, which address screening and child safety [87]. However, addressing these actionable recommendations in one visit may be difficult for children, adolescents, and their families. For youth under 21 with complex conditions, Asare et al found that patient-centered medical homes (PCMH) offer opportunities to improve screening for serious conditions [88]. Similarly, a meta-analysis by van den Berk-Clark et al. suggested that PCMHs had an overall positive association with better metrics [89]. This demonstrates that if caught sooner, children can be treated and improve their overall health outcomes. Finally, Van Cleave et al. suggests identifying CYSHCN and their families' priorities for outcomes measurement, focusing efforts on measuring and collecting information that is important to understand longitudinal health outcomes [90]. Together, these considerations could provide a roadmap to better assess health outcomes in children and youth with high risks.

Future Directions for Measures

A more comprehensive set of valid, reliable quality measures would help drive better care for pediatric and adolescent patients. Coordinated efforts across organizations could help create consistent guidance across the industry and help health care organizations anticipate provider and patient needs as they move across the continuum [84]. Further, more longitudinal studies could help better understand the quality of care provided to pediatric patients with conditions of high risk based on core pediatric measures and offer the opportunity to adequately test new measures that will be meaningful to youth and their families. More consistent IT implementations would promote longitudinal data collection to help identify patterns in pediatric care delivery and outcomes [36]. However, a lack of capital investment and limited patient digital literacy and internet access could create barriers to collecting robust data across the continuum [37].

Value-Based Payment Models for Pediatric Care

The current payment landscape for health care services is quite complex. Value-based payment (VBP) models, which move beyond traditional fee-for-service reimbursement, have been a focus of innovation in both public and private sectors for over two decades. Value-based payment encompasses a wide variety of models/strategies aimed at maximizing health care value gained by increasing coordination, cost efficiency and quality. By using methods that link health care payment and incentives to provider performance, VBPs provide intrinsic benefits to patients, providers, and payers. While most of the previous work has been in adults, VBPs have the potential to greatly enhance pediatric care and provide dividends long into the future. This section will describe how VBP can facilitate more effective care coordination and management, increase transparency of services provided across the system, and reduce avoidable high-intensity service utilization while optimizing utilization of services for youth with medical, behavioral, and social health care needs.

Value-Based Payment

In the private sector, employer sponsored plans began exploring the use of VBP in the 1990s [91]. However, it was not until the 2000s that private insurers began to incorporate pay for performance and incentivizing quality improvements in addition to cost containment strategies [92]. Later in the 2010s, VBP models evolved further to include the shared risk arrangements for providers and payers [92]. Risk refers to the ability to hold financial responsibility for health care quality and cost. VBP models could incorporate upside risk (i.e. financial gain from improvement) and/or downside risk (i.e. potential financial loss or penalties for poor performance) [93].

VBP progress in public payers significantly accelerated with the introduction of the Centers for Medicare and Medicaid Services (CMS) Innovation Center which was established to test and scale innovative ways to provide better care, healthier people, and smarter spending [94]. The Innovation Center has been at the forefront of testing and developing alternative models of health care payment that account for the complexity of care coordination, especially for high-need groups. Value-based purchasing models employ strategies such as shared savings, bundled payments, Total Cost of Care (TCOC) accountability, multi-payer alignment, and shared risk. Examples of these models include: Comprehensive Primary Care Plus, Bundled Payments for Care Improvement Initiative (BPCI), and the Oncology Care Model. Others seek to build an accountable care relationship that establishes a provider as accountable for the quality of care and total cost for a defined beneficiary group [95]. Accountable Care Organizations (ACOs) usually emphasize care coordination to ensure appropriate service utilization, improve quality, and promote responsible stewardship of resources. Many ACO models also utilize quality metrics to connect care quality to payment. Recent ACO models include LEAD Model, ACO REACH, ACO Primary Care Flex, and Kidney Care Choices.

CMS Innovation Center's approach includes rigorous evaluation to assess demonstration results. While testing from multiple models has found that care coordination does decrease readmissions and costly expenditures, decreases in TCOC were mixed when accounting for financial incentives and lower acuity care costs [96, 97]. Models have also observed that care coordination could reduce/avert higher acuity services and more serious impairment in the future [97, 98]. The Accountable Health Communities (AHC) Model tested screening and navigation to community resources including housing, food, transportation, utilities and interpersonal violence. This model found that individuals who received AHC services had lower health care expenditures, inpatient stays, and ED visits [98]. Qualitative data indicate that participants reported being more proactive and seeking less acute care because of care navigation [99].

Challenges and Opportunities for VBP in Children

Previous VBP models have almost exclusively focused on adult populations, with many on the Medicare population (i.e. likely aged 65+). While some elements might be transferable to children, many will not. The Medicare population is more likely to incur higher costs, with more chronic conditions than children [99]. Medicare claims provide a level of detail and consistency that are not widely available from other sources, including private payers and Medicaid. While adults account for a significant share of overall health care costs, among children, those with complex conditions account for a disproportionate share of health care expenditures. The health care experiences and providers are different when comparing children and adults. However, previous meta-analytic research has shown that similar to adults, models of integrated care improved outcomes for children with complex medical needs [100]. As CMCs may appropriately require high levels of healthcare services due to the severity of their impairments, integrated care models have the potential to increase efficiency of services while maintaining care quality and outcomes.

Previously identified challenges in quality measurement are compounded by the fact that VBP models often rely on these measures for payment. Inconsistencies in measure use make it difficult to accurately quantify success. In addition, it is important to note that many pediatric measures are developed for general populations and may not accurately account for the complexity of care for CMC [101]. This severely impacts the development of norms/comparison groups and payment targets. To address this issue, some VBPs tie payment to the simple collection and reporting of measures, whereas others connect payment to performance on those measures.

While the evidence base for VBP in this population is expanding, there is some indication of the potential opportunities in this area. There are significant opportunities for future cost improvement with early intervention in young patients that may not be possible in advanced age [101]. Reductions in the progression to more serious impairment due to early intervention have the potential to pay dividends in the way of decreased costs for decades to come. While there are more challenges in implementing and evaluating VBP models in pediatric populations, the potential benefits, particularly to Medicaid, are substantial. Previous economic research has shown that Medicaid-enrollment *at birth* had a positive impact on the long-term health status of vulnerable children (e.g. low birth weight and/or preterm infants) that extended to the next generation where their offspring were significantly less likely to have similar conditions at birth [103].

Medicaid and CHIP

Medicaid and CHIP continue to be the largest single source of health care coverage for children in America. Enrollment data as of August 2025 indicate that 37.8 million children were covered by these public insurance programs across the states and the District of Columbia that report enrollment data [104]. This represents 47.7% of total Medicaid and CHIP program enrollment [104]. Among children, Medicaid and CHIP cover a disproportionate share of those with special needs due to disability status and inclusion in out-of-home placement (e.g., foster care). Medicaid covers almost one quarter of the children in the United States with special needs compared to one third of those without [105].

One of the challenges in advancing VBP in children is the variability across state Medicaid programs. This also contributes to the difficulties in calculating incentives and capitation rates. Capitated payments are a way of paying providers an up-front consistent amount for patients over a specified time period. However, incorporating alternative payment approaches in Medicaid beneficiaries has been done in the past. Most notably, CMS Innovation Center launched the Integrated Care for Kids (InCK) model in 2020 aimed to reduce expenditures and improve quality of care for children covered by Medicaid [106]. The model required participants to implement at least one alternative payment model that best fit their state and local context. Most included per-member-per-month (PMPM) capitated payment and financial incentives for reducing costs

[106]. While the demonstration and evaluation are ongoing, early findings indicate broad interest in developing VBP models in pediatrics.

Furthermore, in 2019 the Bipartisan Medicaid Act (HR 1839) created the Section 1945A Health Home option for CMC. While not specifically a VBP, this program does incorporate various elements of VBP by providing additional funds to encourage enhanced services for children at the state level. This law allowed states to offer standard health home services of coordinated care, care management, health promotion, transitional care, patient and family support, and referrals for children with complex medical needs. Specific to this population, CMS required specialized pediatric care, out-of-state access, and data reporting, for which states get an enhanced 90% Federal Medical Assistance Percentage for eight fiscal quarters. In 2022, Medicaid issued guidance to states on developing state plan amendments to include this benefit [107]. To date, no state has pursued this benefit.

The recent CMS Innovation Center models and Medicaid benefit programs demonstrate that there is broad interest in improving health care for children by incorporating integrated care and value-based payment. However, further investigation is necessary to add to the evidence base and provide further justification for wider dissemination. As Medicaid is the largest single provider of insurance to children in the United States, any improvements in care, health outcomes, and more efficient and sustainable use of resources would greatly benefit the public insurance program.

Pediatric Spending and Service Utilization Landscape

It is estimated that Medicaid/CHIP spends $3,321 per enrollee on health care for children each year [46]. However, Medicaid spending for children with disabilities (enrolled through the Katie Beckett eligibility pathway) is almost six times higher than average [105]. Children with special health care needs tend to require more specialty services which are also more expensive. Although CMC represent less than 1% to 6% of U.S. children, they account for about one-third to one-fourth of pediatric health care costs [108, 109, 102].

While specific benefits and eligibility for Medicaid may vary by state, CMS requires that all states provide a minimum level of Early and Periodic Screening, Diagnosis and Treatment (EPSDT) for all enrollees under the age of 21. This EPSDT benefit includes regular screenings for medical, dental, vision and hearing issues and any services required to address those issues, regardless of if it is covered by the state's benefit package. Therefore, CMS requires and pays for services for children that are beyond those covered for other pediatric populations. In addition, approximately 9% of the children with special health care needs in the United States have both Medicaid and private insurance coverage [105]. These children tend to have even higher health care needs and are likely covered by private insurance through parental coverage and public insurance due to disability status. Children with Medicaid and private insurance also tend to have more functional difficulties than those who are covered by only one source [105].

Accelerating State Pediatric Innovation Readiness and Effectiveness (ASPIRE) Model

In early 2026, the CMS Innovation Center announced the Accelerating State Pediatric Innovation Readiness and Effectiveness (ASPIRE) Model. This model is intended to build upon lessons learned from the InCK model and focuses on children with medical and behavioral health needs. Specifically, ASPIRE seeks to improve care experience, efficiency, and effectiveness for children and youth under age 21 enrolled in Medicaid who are at high and rising risk (HRR) for poor health outcomes. ASPIRE will include VBP and care delivery interventions as complementary innovations that work together to address key issues in pediatric care. Care delivery interventions will include care coordination and case management, child and family support, access to care consultation, connection to important services such as medication management (as indicated), transition care, interactive care planning and relationships with non-medical services. This model has an explicit focus on quality measurement to assess the efficacy of the care that children receive by focusing on metrics meaningful to HRR children, youth, and families.

Conclusions

The rising prevalence of pediatric chronic conditions, now affecting nearly one-third of U.S. children, underscores the urgent need for care delivery models that address the full spectrum of needs of at-risk children and youth, particularly those covered by Medicaid and CHIP. Evidence supports multicomponent interventions, including 24/7 care access, child and family support services, patient-centered planning, comprehensive medication management, cross-sector care coordination, services addressing health risks, and supported transitions of care, though the overarching evidence base remains limited by methodological inconsistencies and a lack of standardized, child-specific outcome measures. Strengthening quality measurement infrastructure to appropriately reflect the physical and mental complexity of pediatric care across cross-sector systems, with child-specific metrics and greater emphasis on long-term outcomes, is essential to accurately evaluating intervention effectiveness and informing payment policy. While nearly every chronic condition has antecedents in childhood, the current financing system requires reform that accounts for children's unique needs, service utilization patterns, and payment landscape. Value-based payment models offer a compelling framework for aligning financial incentives with care quality and cost accountability, yet their application to pediatric populations remains underdeveloped, highlighting the need for rigorous model testing. The ASPIRE Model represents a pivotal opportunity to advance pediatric value-based care by integrating coordinated care delivery with accountable payment structures, with the potential to generate lasting improvements in health outcomes, quality of life, and long-term productivity for the nation's most at-risk children and youth.

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