imagine pediatrics™

From Fragmentation to Safe Days at Home:

Pediatric Value-Based Care Reimagined for Children and Youth with Special Health Care Needs

EXECUTIVE SUMMARY

Children with special health care needs represent one of the most complex and rapidly growing populations in healthcare. Nearly 14.5 million children in the United States require care that spans medical, behavioral, and social needs and evolves as they grow and as family circumstances change.

This year, 2026, marks the 20th anniversary of coining the term Value-based care (VBC). VBC was built to improve outcomes by aligning incentives, care delivery, and measurement, and it has driven meaningful progress in the last two decades. But for children with special health care needs, that promise remains unrealized at scale. Most VBC models were not built for the heterogeneity and family-centered nature of pediatric care, so families continue to navigate fragmented systems and inconsistent access.

This paper examines how VBC must evolve to deliver integrated medical, behavioral, and social care that supports both acute and longitudinal needs. For families, success is not only reduced utilization. It is more Safe Days at Home, days when children are stable and supported and caregivers feel confident managing their care.

Emerging models show that when care is built around integration, continuity, personalization, and family partnership, experience, outcomes, and cost all improve. The opportunity now is to scale what works and align VBC with what children and families actually need.

ACTION ITEM QUICK READ

- **Redesign care delivery** — integrate medical, behavioral, and social care through team-based, 24/7 virtual and in-home access
- **Change how success is measured** — adopt Safe Days at Home alongside cost and utilization metrics
- **Reform payment models** — move beyond fee-for-service to reward continuous, multidisciplinary care
- **Stabilize Medicaid and regulatory policy** — reduce coverage churn to support long-term investment
- **Support caregivers formally** — fund training, respite, and peer support as part of the care model
- **Scale what's working** — purpose-built pediatric VBC models are already proven; the opportunity now is adoption

INTRODUCTION

For a decade, before Imagine Pediatrics, Kelli Lewis lived in a cycle she could not break. Her two sons, Ahav and Analiel, are children with special health care needs, each with significant behavioral health needs alongside other medical and developmental considerations. Her children experienced more than 90 hospitalizations combined. Their care spanned multiple providers, therapies, and school-based services, and their needs shifted as they grew, sometimes suddenly, always requiring Kelli to adjust.

When those needs escalated, there were few places to turn outside the hospital. Hospitalization became a recurring part of life, and each episode disrupted not only her sons' routines but the stability of the entire family. Between crises, Kelli coordinated across providers, communicated with schools, and tracked every change in behavior and health. She had to decide, again and again, when to seek help, all while working and caring for her family.

The same pattern kept repeating. A crisis led to hospitalization, then recovery, then the uncertainty of not knowing when the next disruption would come.

A REALITY SHARED ACROSS FAMILIES

This experience reflects the reality for millions of families of children with special health care needs.

Across the United States, children with special health care needs face persistent gaps in access and continuity. Almost half are covered by Medicaid or a combination of Medicaid and private insurance, making these challenges especially pronounced for families navigating a program where access, coverage, and care models can vary widely.

~50%

of children in the U.S. are covered by Medicaid

ONE IN FIVE

children receive adequate care

Only one in five of these children receive care in a well-functioning system, one that includes family partnership, adequate insurance, easy access to services, and preparation for the transition to adult care. More than half of families find it somewhat or very difficult to get their child needed mental health care. These gaps leave families managing complex needs with limited support, often leading to preventable escalation and avoidable hospital stays.

A BETTER MODEL IS EMERGING

When care integrates medical, behavioral, and social needs and is delivered through continuous, team-based support that extends into the home, the pattern begins to change. Proactive, personalized care reduces crises, families gain confidence managing complex needs, and children experience greater stability, improving health and experience while lowering the total cost of care.

THE LANDSCAPE – VALUE-BASED CARE AT 20

The term value-based care (VBC) was introduced in 2006, when Michael Porter and Elizabeth Olmsted Teisberg made the case in Redefining Health Care for organizing the health system around outcomes that matter to patients.

VBC has improved quality, cost, and accountability across many populations, especially when designed for a specific population and delivered at the point of care. But existing models were not built for the full complexity of children with special health care needs. Value-based care has not failed this population. It simply was not built for it.

Where Current Models Fall Short for Children with Special Health Care Needs

- **Models were not designed for pediatric complexity**
  Children with special health care needs represent a highly heterogeneous population, spanning more than 40 conditions with trajectories that evolve over time. Their needs shift with development, requiring care models that can continuously adapt.

- **Fragmented care across interdependent needs**
  When medical, behavioral, and social needs are treated separately, gaps affect the whole child. Nearly half of caregivers report unmet care coordination needs, but children whose coordination needs are met are 12 percent less likely to have unmet mental health needs.

- **Access designed around visits, not needs**
  Care needs arise between visits, but access is still built around scheduled, in-person encounters, and pediatric provider shortages and barriers like transportation and food insecurity make it worse. Families face delays and turn to emergency settings when needs escalate.

- **Payment structures do not reflect how pediatric care is delivered**
  Alternative payment models often keep a fee-for-service foundation that rewards encounters over continuous engagement, ignoring the multidisciplinary, longitudinal, and often non-visit-based care these children require.

- **Outcome measures miss what matters most**
  Utilization and cost matter, but they miss the stability, continuity, and caregiver support that define real progress for these children, leaving what matters most to families underrepresented in how value is measured.

- **Incomplete system visibility**
  Care teams frequently operate with fragmented information across systems, limiting their ability to see the full picture of a child's needs. Caregivers — who hold critical, real-time knowledge about their child — are often positioned as coordinators of care rather than collaborators, left to navigate complex, inefficient healthcare and insurance systems on their own. In a recent Imagine Pediatrics survey of 400 caregivers of children with special health care needs, caregivers reported spending more than 11 hours per week on average managing or coordinating their child's care.

WHAT MUST CHANGE — REDESIGNING VBC FOR PEDIATRIC POPULATIONS

Integrated and Continuous Care
Medical, behavioral, and social care must be delivered together by one familiar team that stays with the family, supporting both acute and longitudinal needs with 24/7 access through virtual and in-home care so intervention happens before needs escalate.

Designed Around the Family Reality
Caregivers bring essential insight and often coordinate complex care across systems, a role tied to increased caregiver burden and more negative healthcare experiences as complexity rises. Grounding care in each family's daily constraints, social circumstances, and home dynamic makes plans more realistic and more likely to succeed, given the well-documented impact of caregiving demands on family health and stability.

Built On a Real-Time View
Integrated care depends on real-time, bidirectional data across providers, plans, families, and community resources, and tools that turn that interoperable data into timely action.

Measured and Funded Differently
Payment must move beyond encounters to support continuous, multidisciplinary care, and success must be measured beyond utilization and cost. The clearest example is Safe Days at Home, days when a child is stable, supported, and able to remain at home and caregivers feel confident managing care.

PEDIATRIC VALUE-BASED CARE IN PRACTICE

What Changes When the Model Works

Delivered together through continuous, team-based care, including virtual and in-home care, intervention happens earlier. Care teams respond in real time with full visibility into the child's needs and family context, moving families away from the familiar pattern of delayed intervention, avoidable escalation, and reliance on preventable emergency and inpatient care.

For Imagine Pediatrics, this approach has delivered:

100,000
children with special health care needs served

300,000+
virtual, digital, & in-home encounters, expanding access beyond traditional settings

8,350
Safe Days at Home delivered, reflecting increased stability & reduced need for acute care

86
Net Promoter Score, far exceeding industry averages (20–60)

5,000+
emergency and urgent care visits avoided, with 80% of children requiring no additional acute care the following month

24%
reduction in admissions per thousand (APK) within 12 months

Three Dimensions of Impact

1. **Improved Outcomes for Children**
   Integrated care enables earlier intervention and reduces avoidable hospitalizations. A meta-analysis of 31 randomized trials found integrated medical-behavioral interventions significantly outperformed usual care on child health outcomes, and a 2025 RCT showed pairing social care with medical care cut pediatric ED visits and hospitalizations by roughly half.

2. **Greater Stability for Families**
   With continuous access to a care team that understands both the child and the family context, care becomes more proactive and personalized.

3. **More Sustainable Costs**
   Because preventable acute utilization drives a disproportionate share of pediatric spending, shifting care upstream lowers cost while improving outcomes.

WHY NOW — AND WHY THIS TIME IS DIFFERENT

Across several populations, value-based care has shown that care improves when incentives, care delivery, and measurement are aligned around outcomes. That foundation is now strong enough to be extended to children with special health care needs, with models designed to reflect their complexity from the start.

Workforce shortages, rising complexity, and demand for care beyond traditional settings expose the limits of existing models. Families have been clear about what works: continuous relationships, timely access, integrated support, and care that fits daily life. The question is no longer whether value-based care can work for this population, but whether the system is prepared to follow what evidence and families have already shown.

POLICY AND PAYMENT CONSIDERATIONS

~50%

of pediatric spending is attributed to children with special health care needs

Children with special health care needs account for nearly 50% of pediatric healthcare spending, yet policy and payment structures remain misaligned with how their care is delivered. For pediatric value-based care to scale, policy and payment must match how care is actually delivered for children with special health care needs and their families.

These children rely on systems that are fragmented, inconsistently funded, and not designed for integrated, longitudinal care. 21.8% of families report needing additional help coordinating care, and nearly one-quarter never receive it. 36.9% of Medicaid-covered children with special health care needs have emergency department visits, and 17.6% cannot access needed mental health treatment.

21.8%

of families report needing additional help coordinating care

36.9%

of Medicaid-covered children with special health care needs have emergency department visits

Policy & Payment Key Priorities:

- **Develop pediatric-focused alternative payment models**
  Move beyond encounter-based reimbursement to support continuous, multidisciplinary care, using mechanisms like shared savings that tie incentives to long-term outcomes.

- **Stabilize regulatory frameworks**
  Policy variability and coverage churn disrupt continuity and deter long-term investment. Nearly 25% of Medicaid beneficiaries experience coverage churn each year.

- **Strengthen and sustain funding pathways**
  Expand state and federal support for integrated, value-based pediatric care, particularly within Medicaid, where an estimated 40% of children with special health care needs are underinsured.

- **Fund technology-enabled, multi-modal care delivery**
  Expand reimbursement for virtual and in-home care, including cross-state telehealth, and cover comprehensive care coordination across medical, behavioral, and social services.

- **Make interoperability a requirement**
  Treat real-time, bidirectional data sharing across providers, plans, and families as a core requirement for coordinated, accountable care.

- **Adopt pediatric-specific outcome measures**
  Expand quality frameworks to reflect stability, continuity, and caregiver experience, including Safe Days at Home.

- **Recognize and support caregivers as part of the care model**
  Family-centered care approaches improve adherence, coordination, and utilization, and the evidence consistently demonstrates that supporting and engaging caregivers improves both outcomes and cost. Formally recognize family caregiving as essential work in line with AAP recommendations, with protections in Medicaid work requirements and employment policy, and fund caregiver assessment tools, training, respite, and peer support.

- **Expand and support the pediatric workforce**
  Reform licensing and credentialing to grow the medical and behavioral workforce in underserved areas and integrate Community Health Workers and Family Navigators into care teams.

CONCLUSION

Twenty years ago, value-based care introduced a powerful idea, organizing health care around outcomes that matter to patients. That framework is now proven, but for children and youth with special health care needs it has yet to be fully realized.

Purpose-built models are already delivering measurable results: fewer preventable emergencies, more Safe Days at Home, and stronger partnerships with families.

What remains is scaling it, with providers, health plans, and policymakers aligning to redefine value around the stability and continuity families rely on every day.

These children cannot wait for incremental change. The model exists. The results are clear. The time to act is now.

Thank You.

For more information, contact us at (833) 208-7770 or visit www.imaginepediatrics.org

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