States in the lead
Case studies of Iowa and New York efforts to improve early childhood health through Medicaid
Preface

For the past four years, with support from the Robert Wood Johnson Foundation, the Child and Family Policy Center has engaged leaders in the health community to focus attention on the topic of “Health Equity and Young Children.” The work involved enlisting recognized experts in the field to serve as advisors and develop a framework for primary health care transformation to promote health and reduce health disparities in the early years. It included engaging a group of exemplary programs and practices as a learning collaborative to delve deeper into exemplary primary care practices that respond to social as well as biomedical determinants of health. It involved compiling a sourcebook describing opportunities under state Medicaid programs to finance more preventive, developmental, and family-centered services for young children (see insert for a listing of other resources).

Much of CFPC’s work has been at the practice and community level, but states also are stepping forward to advance health practices in the earliest years to improve health trajectories and reduce disparities and inequities.

This publication describes two state efforts to transform child health practice in the early years.

Although different in their approaches, leaders in both Iowa and New York recognize the role that primary child health practice can play in responding to young children’s healthy overall development — physical, cognitive, social, and emotional.

Both states have engaged a broad range of stakeholders and leaders, including practitioners, administrators, advocates, and policy makers.

Both have recognized the key role that Medicaid plays in providing ongoing financing and sustainability.

These state case studies were improved by careful review of local experts. The Iowa case study was reviewed by Marcus Johnson-Miller, Michelle Holst, and Rebecca Goldsmith and the New York case study was reviewed by Suzanne Brundage, Kate Breslin, Christopher Cus, and Kalin Scott. All conclusions and any inaccuracies, however, are those of the case study authors and not the funders of this work nor the reviewers.

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Background: Child health coverage in Iowa

In 2011, the Commonwealth Fund ranked Iowa first (tied with Massachusetts) in the performance of its child health system. Iowa ranked high not only for its policies for covering children under Medicaid and the Children’s Health Insurance Program (CHIP), but also for its comprehensive and preventive approach to primary child health services. The Fund noted some exemplary actions Iowa had taken to expand the scope and content of well-child care starting in the early 1990s, including:

- Developing an interagency EPSDT Collaborative to increase screenings and early referrals to diagnostic and treatment services;
- Participating in the second cohort of Assuring Better Child Development (ABCD II) Initiative to deepen the focus on developmental health services; and
- Establishing the 1st Five Healthy Mental Development Initiative that promotes comprehensive and preventive health services for young children, with the goal of transforming well-child care

During the same period, Iowa expanded child health coverage under Medicaid and CHIP by taking advantage of virtually all federal opportunities to expand both coverage and service provision. This included specific actions to expand Medicaid billing codes to cover more preventive health services for infants and toddlers, screen for and follow-up with care coordination services for children identified as at-risk for developmental delays or behavioral concerns, and support through administrative claiming training on practices to develop linkages to community systems of support.

These actions were possible through a state agency partnership between Iowa Medicaid Enterprises (IME) and the Iowa Department of Public Health (IDPH) and its Title V Maternal and Child Health program and supported by the advocacy of multiple health and child policy organizations. The Off to a Good Start Coalition, composed of over 30 health and human service organizations and coordinated by the Child and Family Policy Center, spurred adoption of new federal coverage and service options available in the Child Health Insurance Plan Reauthorization Act (CHIPRA). Support from the Annie E. Casey Foundation for a peer exchange brought a team of ten leaders from Help Me Grow in Connecticut to meet with practitioner, agency, community and legislative leaders to explore opportunities to build on Iowa’s ABCD II work and further expand preventive and developmental health services for young children.

The meeting with Help Me Grow led the Iowa legislature to establish the 1st Five Initiative in FY 2007 as a demonstration effort with a $325,000 state appropriation. The program received an increase of $1 million in FY 2014, bringing the total appropriation to $1,327,887. Over the years, Iowa has expanded state funding for 1st Five and leveraged Medicaid funding — both for specific services provided as part of 1st Five and for administrative management of the program and its ongoing diffusion and incorporation into expected practice. 1st Five utilized the Help Me Grow program model (centralized call center and phone referral process) to support the family practitioners and smaller rural practices common in Iowa by providing care coordination and follow-up, even when the practices themselves did not have the volume to have care coordination staff in-house.
Models like 1st Five are viewed as the future for primary child health care in Iowa and key to achieving Iowa’s goal of being “the healthiest state in the nation.” Such models recognize two important facts: that social determinants play a greater role than medical care in affecting child health trajectories and that the first years of life are critical and foundational to healthy development.

The 1st Five Model

The Iowa Department of Public Health contracts with local Title V maternal and child health agencies to implement 1st Five. Currently, 18 of 22 Title V agencies do so (covering 88 of 99 counties). 1st Five supports health providers in early detection of social-emotional and developmental issues of young children as well as environmental and social determinants that can affect a child’s healthy development. The model includes the coordination of services and resources that address a child’s environmental and social determinants of health, including parents’ well-being. Recognizing this expanded role, 1st Five recently changed the title of its “Care Coordination Specialists” to “Developmental Support Specialists” (DSS).

The DSS job requires personal contact with families and providers as an important step in creating individualized care plans that are family-centered and meet the family’s needs. The scope of family contact activities is wide, including face-to-face visits, telephone contact and written correspondence. Through these interactions, the DSS assists families in making health care appointments, coordinates access to needed support services and follows up with families to ensure that they were able to access the necessary resources and services.

1st Five site coordinators promote surveillance and screening intervals per Iowa’s EPSDT periodicity schedule. The most commonly promoted surveillance tools are Bright Futures and the Child Health Development Record (CHDR). Popular screening tools include the ASQ-3 and ASQ:SE-2 (and to some degree M-CHAT-R/F). The CHDR, completed in the office by the child’s parent or caregiver, includes both child-specific questions about the child’s development and environmental questions related to the caregiver’s situation (stress, depression and changes in life status). 1st Five site coordinators spend the first year of their contract laying the groundwork with providers to implement screening and surveillance into their practice and continue this work throughout the implementation contract phase. The Child Health Specialty Clinics, part of the University of Iowa Health Care system, lend support through provider consultation work.

1st Five offers practitioners training and support to incorporate screening and surveillance into the practice setting and, during the office visit, provides appropriate anticipatory guidance related to the responses as well as to other child physical health conditions.

When responses raise concerns — either about the child’s development or the caregiver and home situation — practitioners can conduct additional assessments and make referrals to subspecialty services (such as developmental or behavioral services). Primarily, though, they connect families to a 1st Five development support specialist to follow up and further interview the parent or caregiver. The 1st Five DSS, who has expertise in child development and family dynamics and training in motivational interviewing, is available by telephone.

The DSS utilizes the surveillance or screening results and the practice’s reasons for referral, then moves beyond the specific responses (such as the identification of parental stress) to examining parents’ concerns. Beyond identifying community resources as well as clinical services to address concerns, the DSS assists with scheduling appointments and follow up.
With a better understanding of parental concerns and children's needs, the DSS matches families with resources and ensures smooth hand-offs. Likewise, the DSS keeps practices updated and follows up with the families regarding their experiences. This work extends well beyond what is typical of care coordination, particularly as it accesses services and resources and seeks to build family initiative through engagement and problem-solving with parents. Currently, 1st Five specialists typically connect children and their families to two or more services or supports. Both families and practices report high levels of satisfaction with 1st Five, particularly in fostering greater parental resilience and efficacy in serving as their child’s caregiver and providing a nurturing home environment.

In addition to supporting primary care practitioners, 1st Five supports community capacity building. 1st Five works to identify new community resources and services and establishes relationships with them. These relationships help 1st Five better match families with resources that better meet their needs. These health liaisons become mavens for accessing and supporting both formal and informal services and resources in the community.

1st Five activities are represented in the following schematic:

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**The Evolution of Financing of 1st Five and Developmental Services for Young Children under Medicaid**

Medicaid covers a large share of the child population in Iowa, but the rates are highest for young children (Table One). More than half of all Iowa children 5 and under are served by Medicaid and a larger share of those are vulnerable to poor health trajectories. Moreover, it is during these years that children have the most well-child visits and encounters with primary health practitioners.

When Iowa first established the 1st Five initiative, it did so solely with state funding. As 1st Five expanded, the General Assembly directed Iowa Medicaid Enterprise (IME) to work with the Iowa Department of Public Health (where 1st Five is housed) to explore ways to leverage Medicaid funding to expand and
sustain the Initiative. Also, as a result of its work under the ABCD II Initiative, Iowa established specific billing codes for services targeted to the healthy development of infants and toddlers. This constituted a way to provide additional services to meet young children’s developmental health needs.

In Iowa, Title V and Medicaid have a unique, long-established relationship. In the 1990s the Iowa CMS 416 rate was under 10 percent for well-child visits. In response, IME started a pilot project, contracting with local Title V agencies to inform newly enrolled Medicaid families of the services available to them under the EPSDT program and care coordination services—helping families get connected to medical homes. This pilot was tremendously successful and IME decided to take the initiative statewide, contracting with Title V agencies across the state to conduct informing services of EPSDT and care coordination.

Child Health Agencies have designated Medicaid providers the status of “screening centers” and maternal health agencies have designated Medicaid providers the status “maternal health center.” These provider statuses are unique to Iowa. Under this provider status, maternal and child health agencies are authorized to provide informing services under EPSDT, medical care coordination, help children and pregnant women enroll in Medicaid through presumptive eligibility and to provide an array of direct services (developmental screening, immunizations, blood lead tests, vision, hearing, caregiver depression, etc.). Title V agencies are able to bill Medicaid for these services under their “screening center” or “maternal health center” provider status. Title V agencies across the state have been conducting informing and care coordination for over 20 years, and Iowa’s CMS 416 rates have increased from 9-11 percent to 80-90 percent.

From the practitioner’s perspective, the major financing for 1st Five under Medicaid comes through reimbursement for well-child visits and additional screens provided in the office. One of the results of ABCD II was the unbundling of developmental screening from well-child visits. Training and other resources are provided to participating 1st Five practices to incorporate surveillance and screening tools into well-child visits. This includes support in organizing the office and in transferring information to the DSS. Since practices refer families to the 1st Five DSS, extensive additional office activity related to that follow up is not needed. States vary widely in the amount of reimbursement provided under Medicaid both for well-child EPSDT visits and for additional screens ordered as a result of those visits—and Iowa provides among the highest reimbursement rates for visits and screens. Table Two shows the reimbursement rates for providers and screens:

*While Medicaid provides this reimbursement for screenings, private insurance generally provide much lower rates, which has been a challenge for practices, since 1st Five is designed for all children, both privately covered and covered by Medicaid or CHIP.

<table>
<thead>
<tr>
<th>Table One: Iowa children 5 and under served by Medicaid, EPSDT screens and rates, and proportion of all children served by Medicaid</th>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Served under Medicaid</td>
</tr>
<tr>
<td>EPSDT screens (visits)</td>
</tr>
<tr>
<td>Screens per child (mean)</td>
</tr>
<tr>
<td>State population</td>
</tr>
<tr>
<td>Medicaid as % of population</td>
</tr>
</tbody>
</table>

*Source: Iowa 416 form submitted to Center for Medicare and Medicaid Services for FY2017 for Medicaid data; Iowa Data Center for Iowa population, July 1, 2017.*
Initially, Iowa’s 1st Five program leveraged Medicaid funding to pay for care coordination for Medicaid enrolled children. Since the 1st Five program covers all children, not just those served by Medicaid, state funds only were used to cover a share of the cost for IDPH to maintain the care coordinators. A significant share of the care coordination utilized federal funding. When Iowa moved from a largely fee-for-service system of reimbursement into a managed care system in 2015, this care coordination was deemed to be duplicative of that provided under managed care.

Aside from direct funding for services, Iowa’s 1st Five program is supported by Medicaid through an administrative contract with IDPH for specific infrastructure building activities, including physician and office practice training, community health liaison activities, data collection, evaluation and continuous improvement practices. Since 1st Five serves all children, whether covered by Medicaid or not, the Medicaid administrative match for IDPH is prorated by the proportion of the 1st Five population served that is covered by Medicaid. This administrative contract provides the infrastructure to support the overall diffusion of 1st Five and its goals to become the standard of care. Some of the sites also leverage private funding (from local foundations and philanthropic organizations) to supplement the funding they receive from the state.

**Implications for other states**

1st Five started as a demonstration program in three sites spanning eight counties. It has grown to cover 88 of Iowa’s 99 counties (although not all practices within those 88 counties are involved). The efforts in Iowa to advance more preventive and developmental health services to young children starting with the child health practitioner itself have evolved over more than two decades.

The experiences in Iowa suggest that the literature on the diffusion of innovation holds in advancing such practice in primary child health care. Innovators and early adopters exist who can be enlisted to test and use new approaches. Once there is a base of adoption, these new approaches can spread to most pediatric practices. Moreover, through providing support for such adoption and diffusion, the state can advance

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**Table Two: Billing codes and reimbursement rates (July 2017)**

<table>
<thead>
<tr>
<th>Service</th>
<th>Code</th>
<th>Iowa Medicaid's maximum reimbursement rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Health Screening (0-12 months)</td>
<td>99381</td>
<td>$88.72</td>
</tr>
<tr>
<td>Periodic Health Screening (0-12 months)</td>
<td>99391</td>
<td>$72.40</td>
</tr>
<tr>
<td>Initial Health Screening (1-4 year)</td>
<td>99382</td>
<td>$95.22</td>
</tr>
<tr>
<td>Periodic Health Screening (1-4 year)</td>
<td>99392</td>
<td>$79.93</td>
</tr>
<tr>
<td>Developmental screening, per instrument, scoring and documen</td>
<td>96110</td>
<td>$61.51 (MD or DO)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$52.28 (nurse practitioner)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$57.07 (screening center)</td>
</tr>
<tr>
<td>Brief emotional/behavioral assessment (e.g., depression</td>
<td>96127</td>
<td>$61.51 (MD or DO)</td>
</tr>
<tr>
<td>inventory) with scoring and documentation, per standardized</td>
<td></td>
<td>$52.28 (nurse practitioner)</td>
</tr>
<tr>
<td>instrument</td>
<td></td>
<td>$61.51 (screening center)</td>
</tr>
</tbody>
</table>

such diffusion and move to scale, particularly as Medicaid provides such a large share of the financing for primary child health practice.

1st Five received a great deal of receptivity from primary child health practitioners, other child health organizations, early childhood systems developers, legislative policy leaders and state agency staff. Many appreciated 1st Five’s methodology of using their expertise and influence to advance the next step in health service delivery, rather than categorizing their work as failing to provide appropriate practice and as obstacles to reform. In this respect, the Interagency EPSDT Task Force and the Off to a Good Start Coalition played key convening roles to support such changes. Moreover, the involvement of policy leaders within IDPH, IME and the Iowa General Assembly, as well as child health practitioners, helped translate what practitioners saw as new opportunities in practice into policies to finance and support that work.

The biggest challenge to this effort has been getting the larger systems—Medicaid and managed care—to devote time and attention to child health. Children are not drivers of health costs. Improving children’s health trajectories often do not provide immediate cost savings, although they hold promise in reducing long-term health care demands and costs.

Many of Iowa’s policy activities on Medicaid have been directed toward containing the rise in overall Medicaid costs, in significant measure due to an aging population and the prevalence of high cost chronic health conditions. The work of advocacy groups like the Child and Family Policy Center has played an important role in bringing people together and continuing to press for action related to child health. IDPH and its maternal and child health division played a lead role in working with IME to establish payment systems under Medicaid.

Regarding the use of Medicaid to finance these reforms, Iowa has built an encompassing structure that finances primary child health practices through payments for well-child care and for additional screenings, which generally covers the cost and expectations associated with these roles. The administrative support through IDPH leverages additional Medicaid funding to cover the needed infrastructure to diffuse the practice, provide for data collection and analysis and support community health liaisons. For some time, Medicaid also has provided direct financing for the provision of the critical care coordination, initially securing matching federal funding for a portion of that work. By having a direct appropriation for 1st Five and then seeking to leverage Medicaid to expand that support, Iowa has also created a structure for maintaining the program in whole, even though some portions may not be eligible for Medicaid financing and some children and families served are not covered under Medicaid.

The development of specific infant and toddler billing codes also has opened the opportunity to secure Medicaid financing for services that are directed toward improving child health trajectories by operating through strengthening the parent or caregiver’s nurturing of and response to the child and the child’s developmental and behavioral concerns.
Appendix

1. More information on the 1st Five Healthy Mental Development Initiative: http://idph.iowa.gov/1stfive


3. Job descriptions for 1st Five Developmental Support Specialists:
   - 1st Five defines the minimum educational requirements needed for the Developmental Support Specialist position. While 1st Five is flexible in the number of persons that share the DSS role in a site (i.e.; two part-time DSS workers, or a site coordinator and another staff share the role), it does require DSS staff to have one of the following qualifications:
     - Registered Nurse; or
     - Health professional with a bachelor’s degree or higher in health education, social work, counseling, nursing, sociology, family and consumer sciences, health and human development, individual and family studies, early childhood, psychology or other health-related field; or
     - License Practical Nurse (LPN) or paraprofessional working under the direct supervision of the 1st Five Site Coordinator or CAH Project Director.

4. Developmental Support Specialists must complete the following trainings within 6 months of hire:
   - Traumatic Stress on Brain Development
   - Post-Partum Depression
   - Active Listening/Motivational Interviewing
   - Child Development and Attachment
   - Working with Families Affected by Substance Abuse Disorders
   - Working with Families Affected by Domestic Violence
   - ASQ and ASQ: SE Developmental Screening Tools
   - Title V Maternal Child Health online training modules: CAH/EPSDT, Informing, Care Coordination and IDPH data system
   - Adverse Childhood Experiences Training Modules
   - Cultural Competency

5. Legislative Language Directing Partnership between 1st Five and Medicaid: “The department of public health shall also collaborate with the Iowa Medicaid enterprise and the child health specialty clinics to integrate the activities of the first five initiative into the establishment of patient-centered medical homes, community utilities, accountable care organizations, and other integrated care models developed to improve health quality and population health while reducing health care costs. To the maximum extent possible, funding allocated in this paragraph shall be utilized as matching funds for medical assistance program reimbursement.”
Introduction: New York and child health under Medicaid

New York has one of the most expansive Medicaid programs in the country. Its Medicaid and CHIP programs cover children up to 400 percent of the federal poverty level, the highest eligibility level in the U.S. Consequently, New York has reduced the percentage of uninsured children to below 3 percent. Approximately 2.9 million New York children are covered by either Medicaid or CHIP at some time during a calendar year. Half of the state's births are financed by Medicaid, and more than half of the population birth to age 3 is covered by either Medicaid or CHIP. The share of children covered by Medicaid is highest among young children and children with special health care needs (see Appendix One for data sources).

Most New York children on Medicaid are covered under managed care. In addition, New York is one of six states that has secured a Delivery System Reform Incentive Payment Program (DSRIP) to transition to value-based care.

Pieces of the Puzzle: Activities leading to the first 1,000 Days on Medicaid

New York began Medicaid Redesign in 2011. Advocates, experts and administrators have since then advanced primary care child health practice, particularly in the first years of life, to improve the child health trajectories by responding to social as well as bio-medical determinants of health.

Activities have included the following:

- The state established a $6.8 million demonstration program (all state funding) in 2016 to implement the HealthySteps program and Medical Legal Partnerships through three-year grants to 19 demonstration sites across the state, drawing from exemplary work in Montefiore Health Systems.
- The state acted under a competitive federal Early Childhood Comprehensive Services (ECCS) grant to focus on improving children's healthy development by age 3 through both policy work and demonstration efforts, including implementing Help Me Grow in three counties.
- The state's Early Childhood Advisory Council (ECAC), particularly its Promoting Healthy Development Working Group, engaged in planning to expand the role of primary child health care in Medicaid, including advancing developmental and maternal depression screening in well-child care and pushing for coverage for nurse home visiting as a service under New York's Medicaid system.
- The United Hospital Fund and Schuyler Center for Children and Families collaborated to explore ways to finance more preventive/proactive health services for young children through value-based care that stresses responding to social and medical determinants of health. They released a report commissioned from Bailit Health, Value-Based Payment Models for Medicaid Child Health, in 2016.
- The state implemented and financially supported a pilot program, Albany Promise, that uses a collective impact model to provide financial incentives to pediatricians with a focus on increasing developmental screenings and connections to Early Intervention to improve school readiness.
• The state established a Value-Based Payment (VBP) Work Group that in turn developed a Children's Advisory Group to design recommendations around strategies to engage providers and MCOs in VBP arrangements covering children.

• Gov. Andrew Cuomo created a First 1,000 Days on Medicaid Initiative and a work group that has become the state driver for further child health policy actions.

All these actions recognize the role that child health practitioners can play in ensuring young children's healthy development and the role that state financing, particularly Medicaid financing, can play in better responding to young children's developmental needs and supporting parents in providing a safe, stable and nurturing home environment. They have set the stage for New York's comprehensive approach to transforming primary child health practice — starting with the Children's Advisory Group on VBP and extending to the First 1,000 Days on Medicaid.

The First 1,000 Days on Medicaid and its potential to transform primary care in child health

Gov. Cuomo directed the New York State Department of Health in August 2017 to create a broad-based First 1,000 Days on Medicaid Initiative, with an inclusive working group to identify and recommend ways to improve outcomes and opportunities for young children and their families through access to childhood health services and expansion of other health and early childhood system coordination and family supports. This effort has become the locus for state policy action and is viewed nationally as being on the cutting edge of advancing primary and preventive health services for young children.

The First 1,000 Days on Medicaid was preceded by development of a Value Based Payment (VBP) Roadmap by the VBP workgroup, which was submitted to the Center for Medicare and Medicaid Services (CMS) in June 2015. That resulted in Medicaid recognizing that social determinants of health (SDOH) play a major role in health outcomes and requiring payers to address at least one social determinant when they enter into VBR arrangements. The social determinants of health workgroup noted the outsize role that SDOHs play for children and advised the state to look more closely at VBP and children. In August 2016, the VBP workgroup approved formation of the Children’s Health Subcommittee and Clinical Advisory Group with the following charge:

• Review the composition of the child and adolescent population and assess the relative fit for VBP arrangements;

• Identify quality measures for potential children's VBP arrangements;

• Identify child-specific measures and assess them for inclusion within existing arrangements; and

• Recommend any necessary policy changes to ensure that the needs of children and adolescents are addressed in a VBP environment.

The subcommittee conducted five in-person meetings and two webinars between October 2016 and July 2017. It drew from the Bailit Health report to highlight both the challenges and the opportunities in promoting more preventive and developmental child health services within a value-based payment system. The Bailit Health report was one of the first national reports to emphasize the need for a different approach to value-based care for children compared with the adult and chronic care populations. The report identified the “value” of providing preventive and developmental care as high but often not subject to specific health care cost savings in the short or intermediate term, which was possible for the chronic
care populations around which many value-based payment systems revolved.

The subcommittee issued its final report for public comment on September 18, 2017, with core recommendations for children (a conceptual framework to guide the state's future deliberations about value-based payment for children); draft recommendations pertaining to a child-specific VBP model; future work focused on children with complex needs; and a measure set that could be applied to VBP arrangements for children. The subcommittee adopted guiding principles that recognized the particular importance of the first three years to lifelong development, as shown below.

Guiding Principles

1. Children are not “little adults.” Typical value-enhancing strategies and disease-oriented quality measures may miss key aspects of child well-being and not be appropriate for all developmental stages.

2. An efficient and effective way to achieve the Triple Aim is to identify opportunities in childhood for health improvement, thereby reducing demand for health care services in the future.

3. Evidence-based childhood interventions can be linked to improvement in overall lifetime health and well-being.

4. Maximizing the healthy growth and development of children today will reduce future health care needs and bring long-term value to Medicaid and other public systems, including but not limited to education, child welfare, and juvenile justice. For these reasons a longer horizon for assessing cost savings must be considered.

5. VBP participation and quality measurement across child-serving sectors will yield better improvements in child health, development, and well-being.

6. Due to rapid brain growth during early childhood and adolescence, social determinants of health are especially important for children. Reducing exposure to—and mitigating effects of—Adverse Childhood Experiences is also critical.

7. Strengthening systems of care, including family systems, is fundamental to improving outcomes for children.

8. The health and mental health of parents/caregivers significantly influences the health and mental health of children. In particular, quality maternity care and behavioral health care for caregivers is critical for setting children on an equal footing toward lifelong health.

9. Access to high-quality primary care is essential.

10. Access to specialty care, especially for maternal and child behavioral health, should be integrated into primary care settings to ensure appropriate access. Access to community-based services that support health should also be improved.

11. Current investment in children’s health may not be sufficient to fully meet their unique needs.

Drawing from this work and these guiding principles, then-Medicaid Director Jason Helgerson announced a new focus for Medicaid Redesign in New York — the First 1,000 Days on Medicaid initiative. This initiative recognized the child’s first three years are the most crucial years of their development.
The First 1,000 Days on Medicaid initiative brought together a large array of stakeholders in a series of four work group meetings between August and November 2017. It was the result of leadership, vision and active participation from the Medicaid director and his office. The work group, chaired by Nancy Zimpher, a national leader in educational issues and cross–system collaboration, was charged with developing a 10-point agenda to enhance access to services and improve outcomes for children on Medicaid in their first 1,000 days of life.

The workgroup was chaired by Nancy Zimpher, the former Chancellor of the State University of New York and a national leader in educational issues and cross–system collaboration, and Mary Ellen Elia, Commissioner of the New York State Education Department. Vice chairs were Kate Breslin, President and CEO of the Schuyler Center for Analysis and Advocacy, and Jeffrey Kaczorowski, MD, Senior Advisor, The Children’s Agenda, and Professor of Pediatrics, University of Rochester. Other key partner organizations included the United Hospital Fund and Albany Promise. The United Hospital Fund, with a core leadership team, served as the backbone organization in managing the inclusive process and provided facilitative leadership through its staffing of the process.

The work group was diverse, with active participation from over 250 experts and stakeholders, including champions from the child health practice community, education, child advocacy, early childhood and other health and medical care and financing communities, and leadership from New York's state Medicaid agency. Through an iterative decision-making process, the work group brainstormed hundreds of ideas, then grouped them into 23 possible action areas for the state.

Finally, the work group prioritized the top ten as recommendations for action (see Appendix Two for a description of each recommendation):

1. Create a Preventive Pediatric Clinical Care Advisory Group
2. Promote Early Literacy through Local Strategies
3. Expanding Centering Pregnancy
4. Establish a New York State Developmental Inventory Upon Kindergarten Entry
5. Expand Statewide Home Visiting
6. Require Managed Care Plans to Have a Kids Quality Agenda
7. Advance Data Systems Development for Cross-Sector Referrals
8. Braid Funding for Early Childhood Mental Health Consultants
9. Make Parent/Caregiver Diagnosis an Eligibility Criteria for Dyadic Therapy
10. Pilot and Evaluate Peer Family Navigators in Multiple Setting

Gov. Cuomo reviewed the work group’s agenda and committed to implementing the recommendations as a 2018 State of the State initiative. The Governor’s Executive Budget proposed and the state legislature appropriated $2.9 million for 2018-2019 and $11.6 million in 2019-2020 to implement them. Much of the funding was directed to additional demonstration and program expansion efforts around Centering Pregnancy, home visiting, peer family navigators, dyadic therapies, and infrastructure development. All these reflect different service and care coordination enhancements to primary and preventive care.
discussed as part of a high performing medical home in the Medicaid and Young Children Sourcebook produced by the Child and Family Policy Center in October 2018.

One recommendation set the stage for even broader changes to Medicaid financing. It called for establishing a preventive pediatric care advisory group specifically focused on transforming primary and preventive health care for young children. The group is now operational and working on three tasks:

1. Develop a framework/model for how to best organize well-child visits/pediatric care in order to implement the Bright Futures guidelines; 
2. Identify barriers, incentives and new system approaches for doing what is expected of providers of children’s health care; and 
3. Make recommendations to the New York State Medicaid program on how to work with managed care organizations and providers to turn Bright Futures implementation guidance into routine practice.

The advisory group’s goal is to define a 3.0 model for pediatric primary care by the end of 2018 and determine the actions needs to implement, finance and sustain it. The advisory group is reviewing models across the country, with a focus on reshaping the pediatric office practice, the provision of care coordination that addresses social and bio-medical determinants of health, and effective and completed referrals to needed services in the community. Although the charge to the advisory group is around redesigning primary care practice for all children (0-17), the advisory group is placing special emphasis on the recommendations and priorities of the First 1,000 Days on Medicaid initiative.

In related efforts, the Early Childhood Advisory Council has convened a working group to improve children’s healthy development through place-based strategies, with a particular focus on addressing child health and development needs in high-poverty communities. Local ECCS grantees also are focusing on developing enhanced responses within those neighborhoods for very young children (birth to 3) through the primary health care office and Help Me Grow. The Regents Early Childhood Work Group Blue Ribbon Commission continues to play a core role in the First 1,000 Days on Medicaid work, critical for maintaining a holistic and integrative approach to improving young children’s healthy development.

**Discussion**

New York is a large and complex state, with much innovation occurring at the local level in both practice and financing in the early-childhood field. Many of the individual efforts are worthy of specific attention as models for possible further implementation and scaling — particularly those funded as demonstration projects to promote expanded services and activities within pediatric primary care.

What makes New York’s actions potentially ground-breaking is the broad base of stakeholders and champions involved and the explicit effort to transform pediatric practice through the state Medicaid financing system to adhere to follow Bright Futures guidelines for well-child care. The presence of executive branch leadership through the Department of Health, Medicaid, the Board of Regents and the education system, coupled with leadership from advocacy, foundation, and practice champion communities has focused specific policy-making attention to Medicaid financing and its essential role in advancing child health through comprehensive preventive and developmental services.
Appendix One: New York children and Medicaid and CHIP enrollment

New York has one of the most advanced and extensive Medicaid programs in the U.S. and has reduced the number of uninsured children in the state to 2.7 percent, according to the U.S. Census Bureau’s American Community Survey (ACS) (2017). That’s well below the national average of 5 percent.

Over 2.9 million children are covered through Medicaid and CHIP at some time during the year, and the vast majority of them are continuously enrolled (e.g. covered for the entire year).

There are multiple data sources on the children covered in New York by Medicaid or by Medicaid and CHIP, and they provide different types of information that are useful in describing New York’s Medicaid program and its core role in covering young children.

The ACS and the National Child Health Survey (NCHS) provide information from parent/adult reports on what type of health insurance (public/Medicaid, private, mixture or none) children have. Such reporting tends to underreport the actual percentage of children covered by Medicaid and CHIP but provides comparable information over time. These data sources show somewhere around 40-45 percent of all children in New York are covered by public, means-tested programs (Medicaid, or Medicaid and CHIP). They also show generally higher rates of coverage for young children (under 6) than older children (6-17 or 6-18). The NCHS shows that the rates are very substantially higher for children with special health care needs than those without special health care needs (especially true for New York). These data provide a numerator (children covered) and a denominator (all children) from the same source.

In addition, the state of New York maintains records of who is enrolled in Medicaid and CHIP, both in total (the MAC-PAC has the latest report) and by child age (EPSDT reporting using the 416 form). These data sources do not provide a denominator, but the ACS provides information on the number of children by age groups and designations that can be used as a denominator. Since different states have different eligibility requirements for children in the 18-20 category and New York provides more coverage for children 18-20 than most states, the denominator needs to be selected with that in mind. The MAC-PAC report actually uses a denominator of 0-17-year-olds in its state comparisons, but it may be more appropriate for New York to use 0-20 years.

The United Hospital Fund has a very useful report that provides additional information about children served under Medicaid: Understanding Medicaid Utilization for Children in New York State (2016).

The following are different New York data from these sources. Overall, they collectively show:

1. New York has a low rate of uninsured children, in large measure because of the expansions in coverage for children under Medicaid and CHIP.

2. Overall, depending on the data source and the time period covered (ever covered during the year, covered throughout the year, or covered at a point in time during the year), Medicaid, or Medicaid and CHIP together, cover at least 40 percent of children, and more like 55 percent of children under Medicaid at least some time during the year.

3. The rates of coverage are higher for very young children.

4. The rates of coverage are much higher for children with special health care needs than for children without special health care needs.
The following is New York Medicaid and New York Medicaid and CHIP data from different data sources for the most recent years available.

### New York child Medicaid and CHIP enrollment from various sources

#### American Community Survey: Estimates of insurance and Medicaid/public insurance, 2017

<table>
<thead>
<tr>
<th>Population</th>
<th>Total</th>
<th>Uninsured</th>
<th>% Uninsured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 years</td>
<td>1,376,688</td>
<td>37,073</td>
<td>2.7%</td>
</tr>
<tr>
<td>6-18 years</td>
<td>3,026,456</td>
<td>80,430</td>
<td>2.7%</td>
</tr>
</tbody>
</table>

#### Population

<table>
<thead>
<tr>
<th>Total</th>
<th>Medicaid</th>
<th>% Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-18 years</td>
<td>4,403,144</td>
<td>1,826,170</td>
</tr>
</tbody>
</table>

#### Population

<table>
<thead>
<tr>
<th>Total</th>
<th>Public Coverage</th>
<th>% Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 years</td>
<td>1,376,683</td>
<td>616,537</td>
</tr>
</tbody>
</table>

#### National Survey of Children's Health: Coverage of Children 0-17 with Special Health Care Needs (CSHCN), 2016

<table>
<thead>
<tr>
<th>Total</th>
<th>Public</th>
<th>Private</th>
<th>Public &amp; Private</th>
<th>Unknown</th>
<th>Uninsured</th>
<th>Any public</th>
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</thead>
<tbody>
<tr>
<td>CSHCN</td>
<td>765,082</td>
<td>281,850</td>
<td>339,262</td>
<td>116,559</td>
<td>1,213</td>
<td>398,409</td>
</tr>
<tr>
<td>Non-CSHCN</td>
<td>3,380,674</td>
<td>1,103,544</td>
<td>2,005,017</td>
<td>92,417</td>
<td>60,067</td>
<td>1,195,961</td>
</tr>
<tr>
<td>All children</td>
<td>4,145,756</td>
<td>1,385,394</td>
<td>2,344,279</td>
<td>208,976</td>
<td>61,280</td>
<td>1,594,370</td>
</tr>
</tbody>
</table>

% of CSHCN

<table>
<thead>
<tr>
<th>% of CSHCN</th>
<th>100%</th>
<th>36.8%</th>
<th>44.3%</th>
<th>15.2%</th>
<th>0.2%</th>
<th>3.4%</th>
<th>52.1%</th>
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</thead>
</table>

% of non-CSHCN

<table>
<thead>
<tr>
<th>% of non-CSHCN</th>
<th>100%</th>
<th>32.6%</th>
<th>59.3%</th>
<th>2.7%</th>
<th>1.8%</th>
<th>3.5%</th>
<th>35.4%</th>
</tr>
</thead>
</table>

% of all children

<table>
<thead>
<tr>
<th>% of all children</th>
<th>100%</th>
<th>33.4%</th>
<th>56.5%</th>
<th>5.0%</th>
<th>1.5%</th>
<th>3.5%</th>
<th>38.5%</th>
</tr>
</thead>
</table>

#### MAC-PAC Medicaid + CHIP (some time during year), 2016

<table>
<thead>
<tr>
<th>Medicaid &amp; CHIP</th>
<th>Medicaid</th>
<th>Medicaid/CHIP Expansion</th>
<th>CHIP separate</th>
<th>0-17 population</th>
<th>0-20 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>2,915,972</td>
<td>2,231,347</td>
<td>259,649</td>
<td>424,976</td>
<td>4,494,600</td>
</tr>
<tr>
<td>% of 0-17</td>
<td>64.9%</td>
<td>49.6%</td>
<td>5.8%</td>
<td>9.5%</td>
<td>100%</td>
</tr>
<tr>
<td>% of 0-20</td>
<td>56.4%</td>
<td>43.2%</td>
<td>5.0%</td>
<td>8.2%</td>
<td>N/A</td>
</tr>
<tr>
<td>EPSDT Participation During Year by Child Age, FY 2016</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EPSDT participation</td>
<td>Under 1</td>
<td>1 and 2</td>
<td>3, 4 and 5</td>
<td>19 and 20</td>
<td>All 0-20</td>
</tr>
<tr>
<td>Total participants</td>
<td>182,779</td>
<td>314,738</td>
<td>395,669</td>
<td>237,121</td>
<td>2,658,612</td>
</tr>
<tr>
<td>State population</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of state population</td>
<td></td>
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</table>
Appendix Two: Schuyler Center for Children and Families summary of the First 1,000 Days on Medicaid Initiative (exerpt from report on Schuyler Center website, February 2018)

New York’s First 1,000 Days Initiative

During 2017, at Governor Cuomo’s direction, New York State Medicaid brought together a cross-section of over 200 stakeholders from education, child development, child welfare, pediatrics, and mental health to develop recommendations for how Medicaid could improve outcomes for the youngest New Yorkers, aged zero to three years, nearly sixty percent of whom are covered by Medicaid. The work group developed a set of ten recommendations that are evidence-based, family-focused, cross-sectoral, and informed by child development. … The first 1,000 days of life present a crucial period of opportunity to support optimal development with lifelong consequences, as a child’s brain develops most rapidly during the first three years. … The medical care system, in the form of a pediatrician’s or family physician’s office, plays an outsize role in young children’s lives, because data show that most children receive medical care – well-child visits, immunizations – several times per year. … Because nearly 60 percent of children age zero to three in New York State are covered by Medicaid, the Medicaid program can play an important role in ensuring strong outcomes for a large number of children. …

Recommendations of the First 1,000 Days Medicaid workgroup

Braided funding for Early Childhood Mental Health Consultation. The Office of Health Insurance Programs (OHIP) at the Department of Health (DOH) will convene a design committee colleagues in the Office of Mental Health, Office for People with Developmental Disabilities, Office of Alcoholism and Substance Abuse Services, Office of Children and Family Services, and potentially the State Education Department (Adult Career and Continuing Education Services) to explore innovative approaches to pay for mental health consultation services for early childhood professionals in child care and other early learning settings. Infant and Early Childhood Mental Health Consultation involves a mental health professional partnering with early childhood teachers or other child care staff to infuse activities and interactions that promote healthy social and emotional development, prevent the development of problem behaviors, and intervene to reduce the occurrence of challenging behaviors. It is an evidence-based approach to building the early learning workforce’s capacity to support children’s social-emotional and behavioral development.

Statewide Home Visiting. New York Medicaid will take several significant steps with the goal of ensuring the sustainability of home visiting in New York so every child and pregnant woman who is eligible and desiring of the services receives them. The Office of Health Insurance Programs (OHIP) at the Department of Health will convene a workgroup, likely building upon the NYS Home Visiting Coalition, to identify opportunities for increased Medicaid payment for evidence-based, evidence-informed, and promising home visiting programs. OHIP also will work with the NYS Education Department to explore scope of practice changes that would allow non-clinician home visits to be billable and will launch pilots in three high-perinatal-risk communities to scale-up evidence-based home visiting.

* For detail about the ten proposals, go to the New York State Department of Health website, https://www.health.ny.gov/health_care/medicaid/redesign/first_1000.htm. Credit to the United Hospital Fund, which drafted and edited all of the First 1,000 Days on Medicaid recommendations.
Create a Preventive Pediatric Care Clinical Advisory Group. Medicaid will convene a Preventive Pediatric Care Clinical Advisory Group charged with developing a framework organizing well-child visits/pediatric care to implement the Bright Futures Guidelines, the American Academy of Pediatrics’ standard of care. Providers frequently report that established expectations and standards for pediatric care – including relatively forward-thinking standards such as universal screening for food insecurity – are difficult to implement under the current structures of pediatric care prevent these standards from being implemented. The group would identify barriers, incentives, and new system approaches toward the end of enabling New York pediatricians to implement Bright Futures.

Expand Centering Pregnancy. Medicaid will support a pilot project in communities experiencing the poorest birth outcomes to encourage obstetrical providers serving Medicaid patients to adopt the Centering Pregnancy group-based model of prenatal care. The Centering Pregnancy model has shown dramatic improvements in birth-related outcomes and reductions in associated disparities. It was developed by the not-for-profit Centering Healthcare Institute. The Institute provides participating providers with the curriculum, staff training, and a structure for data collection. It also approves the site where the model is offered. Currently the Centering Healthcare Institute lists 33 sites in New York State that offer the Centering Pregnancy model.

Promote Early Literacy through Local Strategies. Medicaid will launch one or more three-year pilots to expand the use of Reach Out and Read (ROR) in pediatric primary care and foster local cross-sector collaboration focused on improving early language development skills in children ages 0–3.

Require Managed Care Plans to have a Kids Quality Agenda. The Department of Health will work to improve managed care plan performance on child and perinatal quality measures. DOH, working with its External Quality Review Organization, will develop a two-year common Performance Improvement Project (PIP) for all Medicaid managed care plans. Input from child-serving community-based organizations, child development experts, the State Education Department, Office of Mental Health, and others should be considered as part of the development process. The focus of the common PIP could be threefold: 1) increase performance on young child Quality Assurance Reporting Requirements (QARR) measures (well-child visits, lead screening, immunization); 2) enhance rates of developmental, vision, hearing and maternal depression screenings; or 3) improve performance on existing QARR perinatal health measures.

New York State Developmental Inventory Upon Kindergarten Entry. The State Education Department, Medicaid, and other partners will agree upon a measurement tool to assess child development upon Kindergarten entry. A child’s developmental status upon Kindergarten entry has been shown to relate to 3rd grade reading, suggesting that improving child development by this milestone is likely to drive long-term improvements in education and health. Third grade school achievement correlates with high school graduation, and high school graduates have better health outcomes than their peers who did not graduate. A standardized measurement tool at Kindergarten entry would enable (1) population-level tracking of trends over time in child development; (2) assessment of how policy and programmatic changes are possibly affecting child development; and (3) identification of areas (regions of the state, components of child development, etc.) in need of improvement, investment, and policy change.

Pilot and Evaluate Peer Family Navigators in Multiple Settings. The Department of Health will support the development, implementation, and evaluation of nine pilots providing peer family navigator services. Many high-risk families with young children struggle to navigate available resources to help them address both health needs and the social determinants impacting their health. These often hard-to-reach
families may be more likely to consistently interact with non-health community-based resources rather than the health care system. One set of five sites will evaluate the use of peer family navigator services in community settings, like family homeless shelters, supportive housing, early education providers, community mental health clinics, drug treatment programs, and WIC offices. An additional pilot with four sites will focus on family health navigation services in primary care offices.

**Parent/Caregiver Diagnosis as Eligibility Criteria for Dyadic Therapy.** Medicaid will allow health care providers to bill for the provision of evidence-based parent/caregiver-child therapy (also called dyadic therapy) under the child's Medicaid Client Identification Number, based solely on the parent/caregiver being diagnosed with a mood, anxiety or substance-use disorder. The quality of early relationships affects the ability of young children to learn, regulate themselves and form relationships. These developmental processes can be impaired when a parent/caregiver (including extended family and foster parents) has a mental health condition because the relationship with the child is often interrupted as a result of the parent/caregiver's condition. Research has found that when depressed mothers receive treatment for depression only (e.g., medication, cognitive behavior therapy), parenting and relationship problems persist unless there is a specific focus on repairing the parent-child relationship. Evidence-based dyadic treatment models are therapy models in which parents/caregivers and very young children are seen together, and coaching is provided to follow and respond to infant/toddler cues. The goal of these therapies is to repair the parent/caregiver-child relationship in support of healthy child development.

**Data system development for cross-sector referrals.** Medicaid will direct competitive grant funds to purchase a hub-and-spoke data system that enables screening and referrals across clinical and community settings for at least 3 communities. The absence of systems-level mechanisms to connect families to community-based programs is apparent: evidence-based preventive programs are underutilized despite being located in high need areas; families living in areas rich in early childhood programs may be directed to services that don't best fit their needs; obstetricians and pediatric providers, who should be a prime source for making referrals to preventive programs, often do not make referrals; parties responsible for the care of a parent or a child often do not receive critical information; and there is a lack of feedback to providers who initiate referrals. Numerous community efforts to link and support the multiple sectors that touch the lives of young children are currently underway in New York. A common challenge across these efforts is the inability to easily share information and resources across a community to fully benefit the families that are served by different systems.

<table>
<thead>
<tr>
<th>First 1,000 Days Executive Budget Proposal ($ in millions)</th>
<th>FY 18-19</th>
<th>FY 19-20</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Braided Funding for Early Childhood Mental Health Consultations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Statewide Home Visiting</td>
<td>$0.5</td>
<td>$2.0</td>
</tr>
<tr>
<td>3 Preventive Pediatric Care Clinical Advisory Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Expand Centering Pregnancy</td>
<td>$0.1</td>
<td>$0.4</td>
</tr>
<tr>
<td>5 Promote Early Literacy through Local Strategies</td>
<td>$0.1</td>
<td>$0.2</td>
</tr>
<tr>
<td>6 Require Managed Care Plans to have a Kids Quality Agenda</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Developmental Inventory Upon Kindergarten Entry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Pilot and Evaluate Peer Family Navigators in Multiple Settings</td>
<td>$0.2</td>
<td>$1.1</td>
</tr>
<tr>
<td>9 Parent/Caregiver Diagnosis as Eligibility Criteria for Dyadic Therapy</td>
<td>$0.4</td>
<td>$1.8</td>
</tr>
</tbody>
</table>
First 1,000 Days in the budget

The Executive Budget proposed $2.9 million ($1.45 million State) in Medicaid funds toward the First 1,000 Days initiative in 2018-19, with the expectation of $11.6 million ($5.8 million State) in 2019-20 (Medicaid is on a two-year budget). The budget proposals were included in the final enacted budget.

The recommendations build upon and strengthen programs and services for which there is evidence.

And in some cases, the recommendations are a commitment to diving deeper with experts in pediatrics and other fields. In all cases, the First 1,000 Days workgroup recommendations focus on, and were informed by the understanding of the essential role played by parents and caregivers in child development. And, the recommendations all integrate with and build upon existing community-based initiatives. Finally, the recommendations include an intentional and explicit recognition of the need for collaboration beyond Medicaid and health – with education, child care, child welfare, community-based organizations – to focus on results that are not limited to one sector and to strengthen systems across silos.¹ Several of the First 1,000 Days recommendations are closely aligned with the NYS Board of Regents Blue Ribbon Committee on Early Childhood recommendations, and leadership in each agency – Department of Health and State Education Department – have committed to moving forward together.²

References

1 See detail about the proposals at the New York State Department of Health website, https://www.health.ny.gov/health_care/medicaid/redesign/first_1000.htm