Innovative Approaches in Care Coordination and Care Delivery

for Children with Special Health Care Needs among Safety Net Health Plans

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Executive Summary

Association for Community Affiliated Plans (ACAP)-member plans and other managed care organizations have played a critical role in the development of care coordination programs for children with special health care needs (CSHCN) and their families.[1] The purpose of this report is to highlight innovative models used by selected ACAP member health plans to provide care coordination and high-quality care to children with special health care needs, and to provide a qualitative narrative about the range of plan efforts to improve outcomes, access to health care services, and other needed supports.

It is widely recognized that CSHCN benefit from heightened care coordination and care management services; children and families who do not receive care coordination are generally at increased risk of receiving poor-quality, fragmented care. Safety net health plans play an increasingly important role in facilitating coordinated care for children with complex needs, employing innovative technologies, providing targeted resources to patients and provider teams, and coordinating services for this population and their families.

The plans participating in this analysis represent a diverse array of programs. The 12 participating plans included Health Plan of San Mateo (CA), Inland Empire Health Plan (CA), Community Care Plan (FL), CountyCare (IL), CareSource (OH), UMPC *for You* (PA), Neighborhood Health Plan of Rhode Island, Cook Children's Health Plan (TX), Texas Children's Health Plan, Driscoll Children's Health Plan (TX), Health Services for Children with Special Needs (DC), and Children's Community Health Plan (WI). Although plans varied in size, geographic location, and in their innovative service delivery approaches, there were commonalities in the approaches used to provide comprehensive and coordinated care to these vulnerable children. Eight themes emerged:

- **Multiple pathways to care coordination.** Some programs are linked to a specific high-need population (e.g., children in out-of-home placements or foster care) or a state program (a 1915(c) waiver or specific children's program), but plans also provide enhanced care coordination for children enrolled in a Medicaid Managed Care (MMC) program through all eligibility pathways. Plans use an array of approaches and data sources to identify and support children's health and other care needs, including initial health screens, comprehensive assessments, utilization management, predictive modeling, and family and provider referrals.

- **Partnerships with providers.** All plans emphasized the importance of their ongoing partnership and collaboration with providers, from primary care physicians and children's hospitals to home- and community-based service providers. Plans also described the importance of continuity of providers, whether across transitions in settings or program transitions. Plans also mentioned innovative opportunities for communication and ongoing training with providers, such as learning collaboratives.

- **Innovative care coordination.** Plans use one of two care coordination models: a single point of contact in a named care coordinator (supported by additional diverse plan staff), or a team-based model (also sometimes referred to as a "pod" model). Plans mentioned "embedding" care coordination staff at large or high-volume primary care practices, co-location of care coordination staff, or delegation of care coordination activities to care coordination staff in these practices.

- **Integration of behavioral health care with other care.** Behavioral health care is a service of central interest in care coordination for many CSHCN, and plans reported an array of efforts to ensure coordination between behavioral health and other care. Many plans seek to promote coordination of behavioral health services through enhanced information sharing with each child's key providers. Several plans rely on the development and sharing of comprehensive care plans to document all of a member's services, including key behavioral health supports.

- **Supporting non-medical needs of members and families.** All plans described efforts to identify and support non-medical needs for families involved in their programs, including transportation, housing, education, social services, legal support, nutrition assistance, and support for caregivers. Plans described using the screening or assessment

processes in identifying non-medical needs of children and their families, among other approaches, and emphasized the importance of relationship-building and rapport with families in identifying and addressing social determinants.

- **Effective data mining and analysis.** Some plans use predictive modeling and risk stratification approaches with their claims or care management data to identify children in need of support or to determine which children are lacking preventive or other care. Plans share data with "high-volume" providers about gaps in care or other services children need; with the care coordination team to make them aware of the child's full spectrum of care; and through "data dashboards" available to multiple stakeholders to quickly segment and understand plan data.

- **Measuring quality of care and investing in quality improvement.** Since CSHCN are diverse in diagnoses and risk profiles, quality measurement poses a unique challenge. Despite this, plans track process and outcome measures for CSHCN, often within the larger population of all children, as well as care coordination milestones. A few plans also cited the use of measures specific to this population, including polypharmacy and the usage and effects of antipsychotics.

- **Innovative payment models.** Plans reported employing a variety of innovative delivery and financing arrangements. Several plans offer support and incentives to physician practices to become medical home models. Plans also reported incentive payments for providers to finance and promote engagement in the care coordination process, and emphasized that improved care coordination was the mechanism they believed would drive shared savings in the health care delivery arrangement.

Plans also offered insight into common challenges that they face in serving this complex population of children and adolescents. Access to and quality of information or data was cited as a challenge by several plans. The complexity of serving a high-need population often adversely impacted by an array of social determinants of health was also mentioned by a number of plans. Finally, changes in a state's delivery system, such as implementation of large new programs, can require major shifts to existing plan processes and programs.

Despite those challenges, this report illustrates the wide range of innovative care coordination and care delivery strategies serving CSHCN employed by safety net health plans. Plans use predictive modeling; comprehensive assessment tools; colocation and embedding of care coordination staff; unique and diverse care coordination staffing approaches; expanded communication with providers via learning collaboratives and grand rounds; novel outreach to families, such as through texting campaigns; value-based purchasing and shared savings programs; and innovative quality improvement programs. Safety net health plans continue to innovate and implement new ideas in order to improve care coordination, access and quality for these children and their families and caregivers. Through this important work, plans can transform care for our most vulnerable populations and offer an example for high quality Medicaid delivery systems across the nation.

Introduction

Children with special health care needs (CSHCN) are defined by the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) as **"... those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."**[2] These children may also be described as "children with medical complexities"—a subgroup of CSHCN who often require intensive health care and social services that span a wide range of specialties and systems.[3] It is widely recognized that this population benefits from heightened care coordination and care management services. Children and families who do not receive care coordination are generally at increased risk of receiving poor-quality, fragmented care.[4]

Medicaid Managed Care Organizations (MCOs) are playing an increasingly important role in facilitating coordinated care for children with complex needs.[5] Plan administrators are using innovative technologies and data systems to identify potentially vulnerable enrollees, provide targeted resources to patients and provider teams, and bridge medical, behavioral, and social services for this population and their families. Specifically, Association for Community Affiliated Plans (ACAP)-member plans and other managed care organizations have played a critical role in the development of care coordination programs for children with special health care needs and their families.[6] The purpose of this report is to highlight innovative models used by selected ACAP member health plans to provide care coordination and high-quality care to children with special health care needs and to provide a qualitative narrative about the range of plan efforts to improve outcomes, access to health care services, and other needed supports.

Health Care Service Needs for Children with Special Needs

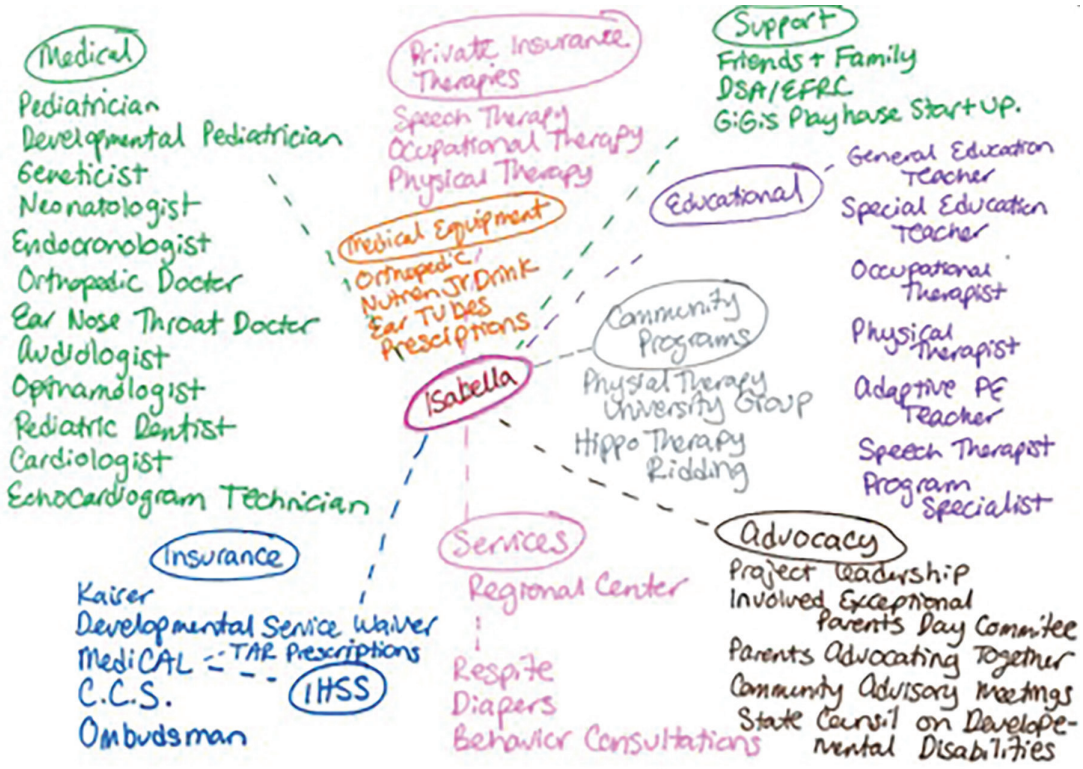
Children with special health care needs comprise 15.1 percent of all children in the United States.[7] Within this broad population of children, there are various subgroups who represent substantial differences in medical complexity, functional limitations and resource needs.[8] One of these subgroups, children with medical complexities (CMC), are medically fragile children who have the most intensive health care needs of all CSHCN and are at risk for frequent or prolonged hospitalizations (both acute and long-term care). They often rely on adaptive technology and durable medical equipment (ventilators, oxygen, feeding tube), multiple medications, and/or home care for sustaining a basic quality of life.[9] The broad group of CSHCN also includes youth and children with behavioral health conditions, such as conduct disorder, diagnoses of depression, or substance use disorders, affecting millions of children per year.[10] Other CSHCN include children with developmental disabilities, children with non-chronic but serious health conditions (such as childhood cancers), and children with common chronic conditions that require ongoing management (such as asthma or diabetes).[11] Finally, children in out-of-home placements (typically in foster care systems) are often grouped with CSHCN in Medicaid programs and receive the additional supports provided to other CSHCN, as they are often at risk for similar health issues such as behavioral health conditions.[12]

Through much of the 20th century, many children with severe, chronic and complex medical conditions did not survive infancy.[13] Advances in pediatric health care have greatly improved the lives and longevity of children born prematurely and those with serious congenital and genetic illnesses. The 2009–2010 fielding of the National Survey of Children with Special Healthcare Needs estimated there were over 11 million children with special health care needs.[14] Estimates suggest that this population is due to double over the next decade. This substantial increase in childhood disability will result in even more intensive health care use and care coordination needs across a variety of services and specialties.[15] It is therefore crucial to better understand the care models that are most effective in meeting the needs of these vulnerable children.

Health care delivery systems in the United States are increasingly faced with the challenge of providing effective and efficient services to this growing population of medically vulnerable children. Monitoring and maintaining the health of children with special health care needs often requires a team of clinical specialists, medication and functional therapies, and assistive technology and equipment.[16] It is important that these services are integrated across a variety of locations, including the primary care medical home, tertiary care centers and hospitals, rehabilitation units, transitional care facilities, the home, and schools.[17]

In addition to needing a multitude of health care services, CSHCN and their families often have a variety of social needs which are often only served through under-staffed and under-funded services, via multiple diverse and diffuse social service systems. These services include disability-focused programs, in-home care, legal services, special education, transportation, and educational programming.[18]

Services provided by several clinical specialists and service providers in various health systems and social service systems can easily become fragmented and families often lack comprehensive care plans for treatment.[19] When this occurs, providers struggle to share information, bridge clinical gaps, and deploy valuable resources. Families, too, are faced with the daunting challenge of navigating a complex health care system when multiple types of services are so urgently needed. In order to meet the multi-system needs of these children, policymakers and providers have recognized the importance of implementing care coordination strategies and best practice models to ensure that services are uninterrupted, comprehensive, and easily accessible.[20] The ideal care model for CSHCN requires expanded attention in a number of areas, including provider training and education, enhanced decision-making support and family centeredness, and expanded access to information and care coordination supports. Through a primary care medical home model, these children and their families can access support through coordinated health care that places the child and family at the center of care, promoting partnerships among physicians, families, and other community agencies to meet the unique care needs of each child.[21] The graphic on the following page offers an illustration of this concept, in one family's visual depiction of the complex constellation of medical, educational, social and other supports involved in the care of their child Isabella (image reprinted with permission from the Villafaña family and the Lucile Packard Foundation for Children's Health).



Care map image courtesy Lucile Packard Foundation for Children's Health and the Villafaña family.

Medicaid Coverage for Children with Special Needs

Since its authorization in 1965, Medicaid has evolved into a critical source of health care coverage for children nationwide. In addition to providing health insurance to low-income adults and people with disabilities, Medicaid also currently covers more than 40 percent of all children in the United States – approximately 32 million.[22] Children have benefitted from the program's expansion over the past several decades, and services provided to children now account for about 20 percent of all Medicaid expenditures.[23] Beyond providing essential coverage to millions of children from low-income families, the federal-state partnership is also playing an increasingly important role in the lives of children with complex health care needs.

Over one-third of all children with special health care needs (nearly four million children) are covered by Medicaid programs.[24] Children with complex medical conditions specifically, although they make up only six percent of all children enrolled in Medicaid, account for roughly 40 percent of all pediatric Medicaid expenditures.[25] Inpatient care represents the largest share of these costs, and children with complex chronic conditions account for approximately 25 percent of all pediatric patient stays and nearly 50 percent of all pediatric hospital charges.[26] The high costs of care for this population are incurred across inpatient, outpatient, and community-based systems of care, and borne not only by the Medicaid program but also by families themselves, many of whom undergo financial hardship as a result.[27]

Medicaid programs can vary in their delivery models, services carved out of managed care programs, special care coordination initiatives, and other key features. The table below provides a highlight of some innovative approaches in different state Medicaid programs to the financing and delivery of care for CSHCN.

As evidenced in the table, several states have pursued innovative strategies in recent years to reform and modernize the delivery of services for their medically complex Medicaid children. Many have shifted from traditional fee-for-service models for this population toward capitated payment arrangements.[32]

Under Medicaid Managed Care (MMC), Medicaid MCOs receive capitation payments and finance and coordinate Medicaid health benefits and other services, under contract with the state Medicaid agency.[33]

Innovative Approaches to Medicaid Coverage and Financing for CSHCN	
Colorado	The Health First Colorado Buy-In Program for Children with Disabilities lets families of children with a disability 'buy-into' Health First Colorado (Colorado's Medicaid Program) if the family's income is too high for Health First Colorado or Child Health Plan *Plus* (CHP+). If the child qualifies, the family pays a monthly premium to be in the program.[28]
Washington	Great LINCS is a federally awarded three-year grant which strengthens care coordination across the State for families of CSHCN by increasing access to statewide resources, reaching out to community partners, Medicaid providers, and pediatric primary care physicians to increase the rate of families reporting being in a medical home.[29]
Ohio	Rainbow Babies and Children's Hospital in Cleveland created a complex care program, including the engagement of a multi-disciplinary care team, to provide care coordination services for CSHCN on Medicaid.[30]
Indiana	Indiana Children's Special Health Care Services (CSHCS) through the State Department of Health provides supplemental medical coverage to help families of children who have serious, chronic medical conditions, age birth to 21 years of age, who meet the program's financial and medical criteria. Care coordination services offered through the program include assistance with locating peer support groups and community support services in their area and educating families on adolescent transition to adult health care and services.[31]

Medicaid MCOs play an increasingly important role in facilitating coordinated care for children with complex needs. Although persons with complex conditions and disabilities historically have been maintained in fee-for-service, state Medicaid agencies are increasingly enrolling these individuals into managed care arrangements.[34] As of 2016, 16 state Medicaid programs reported that CSHCN are always enrolled in managed care, while another 21 states reported some enrollment of CSHCNs in managed care. Just two states reported CSHCN are always excluded from managed care.[35] MCOs can often deploy innovative approaches to care management and care coordination in new ways; Medicaid plan administrators are increasingly able to identify members in need of enhanced support, provide targeted resources to patients and provider teams, and integrate diverse services.[36, 37] Evaluations of such practices within MCOs have found that the provision of comprehensive and integrated health care can result in measurable clinical health improvements and cost savings.[38]

There are multiple pathways for CSHCN to become enrolled in Medicaid MCOs. The two main factors for determining eligibility criteria for Medicaid are whether the individual falls within a category covered by Medicaid and whether the individual's household income meets the eligibility threshold.[39] Additionally, states can extend Medicaid coverage to other groups, including children with severe disabilities who live at home but qualify for institutional level of care without regard to the family's income (Katie Beckett programs) or children who meet the SSI disability criteria with income up to 300 percent of the federal poverty level who pay a premium to Medicaid (Family Opportunity Act Buy-in).[40] There are also children with special needs in Medicaid MCOs who do not have an SSI determination and enter Medicaid via an income categorical eligibility only. MMC plans have found ways to identify and support these children.

In addition to the major mandatory eligibility groups and optional coverage groups for Medicaid, states may request waivers, such as 1115 Demonstrations or 1915(b) and 1915(c) waivers, from the Centers for Medicare and Medicaid Services (CMS) to cover additional groups, offer additional services, or implement delivery system changes. The 1115 Demonstrations give states additional flexibility to design and improve their programs and to demonstrate innovations in service delivery and can be used to cover people who do not fit into a traditional or current Medicaid eligibility category.[41] These demonstrations can be used to increase access to providers and health care, improve outcomes, or increase efficiency or improve quality of care through delivery system reforms.[42] As children with disabilities have not historically been enrolled into MMC, demonstrations and waivers represent states' only opportunity to enroll these children into managed care arrangements which provide access to the heightened care coordination they need.

Since CSHCN span such a wide array of health concerns and conditions, health care researchers have struggled to develop broadly applicable care delivery and management protocols or quality measures for CSHCN.[43] In addition, due to small sample sizes of children with rare complex conditions, it also can be difficult to develop disease-specific quality measures for CSHCN.

Medicaid managed care has led the way in developing and monitoring quality measures for high risk populations.[44] Nearly all state MMC contracts have some provisions targeting CSHCN, the most common of these are requirements for identification of CHSCN

(22 states), care coordination across children's agencies and programs (16 states), inclusion of pediatric providers in networks (13 states) and inclusion of pediatric Centers of Excellence in networks (12 states).[45] In addition, MMC allows for more budget predictability and has the ability to provide improved care management, coordination and access to CSHCN.

Safety net health plans have been at the forefront of these efforts, and have played a critical role in the development of care coordination programs for children with complex health care needs. These organizations have strong links with other safety net providers—community health centers, public and children's hospitals, and other providers – to ensure that children have access to patient-centered care; design creative care coordination models; and deploy innovative data-driven solutions. Through these efforts, safety net health plans are leading the way in providing care that is of higher quality, more integrated, and better coordinated for children with complex medical conditions and their families than traditional service delivery models.[46]

As state Medicaid programs expand MMC coverage for this high-need population, an understanding of the successes and challenges experienced by safety net health plans serving this population can offer valuable insight on successfully caring for CSHCN in Medicaid. To remain consistent throughout this report, we will refer to the varying populations served by safety net health plans as CSHCN. Although each plan provides coverage to different subpopulations of CSHCN, these children all share common care needs and can benefit from community-based services, access to a broad array of primary and specialty providers, elevated care coordination and care management.

To further explore and understand the mechanisms by which plans are addressing the needs of this vulnerable population and their families, NORC at the University of Chicago and ACAP conducted semi-structured interviews with staff from twelve ACAP member plans across nine states. These plans were identified as a diverse subset of safety net health plans with innovative programs serving children with special

health care needs. Plan staff typically included members of leadership (chief executive officers, chief medical officers, and chief operations officers), care coordination staff (directors of care coordination, care coordinators, and directors of nursing), and staff specific to pediatric programs or targeted programs serving the target population (e.g., a pediatric medical officer or program directors). A list of participating plans and their staff is available in the Acknowledgments section in Appendix A. A list of the discussion topics is available in Appendix B. The findings from these interviews are detailed in the following sections.

Participating Safety Net Health Plans		
Plan Name	**State(s) where plan operates**	**Types of CSHCN served**
Health Plan of San Mateo (HPSM)	California	Children with physically disabling medical conditions that are eligible for care under CCS
Inland Empire Health Plan (IEHP)	California	Children with physically disabling medical conditions that are eligible for care under CCS
Community Care Plan (CCP)	Florida	Children with medically enhanced cases/care needs
CountyCare	Illinois	Children with special needs
CareSource	Ohio	Children with special health care needs; children in the custody of the state (foster care and adopted children)
University of Pittsburgh Medical Center Health Plan (UPMC)	Pennsylvania	Children with special health care needs, children with home care service needs
Neighborhood Health Plan of Rhode Island (NHPRI)	Rhode Island	Children with special health care needs; children in out-of-home (foster care) placements
Cook Children's Health Plan (CCHP) - STAR Kids	Texas	Children with special needs, children eligible for SSI, children in the State's Medically Dependent Children Program waiver (MDCP)
Texas Children's Health Plan (TCHP) - STAR Kids	Texas	Children with special needs, children eligible for SSI, children in the State's Medically Dependent Children Program waiver (MDCP)
Driscoll Children's Health Plan - STAR Kids	Texas	Children with special needs, children eligible for SSI, children in the State's Medically Dependent Children Program waiver (MDCP)
Health Services for Children with Special Needs (HSCSN)	Washington, D.C.	Children and young adults up to age 26 who receive SSI
Children's Community Health Plan / Care4Kids	Wisconsin	Children in out-of-home (foster care) placements

For more information about any of these health plans, please visit the ACAP **website**.

Findings

Participating Plans

The plans participating in this analysis represent a diverse array of programs. Some plans care for children with special health care needs within their larger managed care populations, not in a stand-alone program, but with additional supports, services, and enhanced care coordination. Other plans have designated, distinct programs, such as those serving children in out-of-home (foster care) placements or those in specific state programs (e.g., 1915(c) waivers or the California Children's Services (CCS) program). Virtually all plans noted that many children enrolled in Medicaid without designation of disability (e.g., SSI) or enrolled in special programs like CCS may nonetheless have special health care needs and the plans work to identify and support these families in their broader membership as well.

Most plans highlighted in this paper operate in portions of single states, some in areas of just one or two counties. However, these are often in areas comprising the most populous urban and suburban areas in the state. Most plans are responsible for the full gamut of comprehensive Medicaid coverage, including services not typically used by traditional MMC populations, such as home and community-based long-term services and supports. The most common carve-outs mentioned were for behavioral health services—a common Medicaid carve-out, but an important area of services for this population—and 1915(c) waiver services.

Pathways to Care and Care Coordination

As described in previous sections, children with special health care needs are unique in their multiple and often complex care needs. Care needs may be both more substantial and more numerous than the general pediatric population, requiring ongoing management to ensure adequate and appropriate care and close coordination among services to ensure communication among health care providers and avoidance of duplicative or contraindicated services. For example, one child may require private duty nursing at high levels to address multiple support needs; another child who is high-functioning but with neurological or developmental concerns may require the care of eight different physician specialists related to different body systems. In each case, additional attention must be paid to the ongoing monitoring and coordination of care. While families and caregivers play a central role in managing and coordinating the care for their children with special health care needs, additional support in identifying, accessing, and coordinating needed services is a key role that health plans play to support children in this population.

As noted above, safety net health plans' programs for CSHCN take different forms. While there is variation among plans, these programs (and children's pathways to care and care coordination) take two primary forms.

> *While* **Health Plan of San Mateo** *currently uses a comprehensive health assessment in its program, staff are in the process of developing a new assessment tool as a part of a care coordination redesign effort. The new assessment will likely be launched in early 2017; currently, the plan is taking advantage of its consumer advisory panel to obtain feedback on the new assessment from patients and families, input the plan described as "invaluable."*

Some programs are linked to a specific population (e.g., children in out-of-home placements or foster care) or a state program (a 1915(c) waiver or specific children's program). The children enrolled in programs such as these are generally all considered high-need and in need of enhanced care coordination (although plans may stratify these groups further to assist in delivering appropriate and targeted care coordination). Once children have been enrolled in a health plan, the first step in the care planning and care coordination process is typically a comprehensive assessment. While new MMC regulations implemented screening requirements population-wide in managed care, these plans are typically using more comprehensive and

multi-step assessment processes in order to completely characterize each child's care needs. Some plans (such as the STAR Kids plans in Texas and Children's Community Health Plan's Care4Kids program) additionally use a preliminary health screen in advance of the comprehensive assessment, to identify and prioritize the most pressing needs for the child, to facilitate immediate access to care, or to inform the assessment process. While the status of each enrollee as a CSHCN is pre-established in programs like these, plans still employ assessment mechanisms to gather information and inform the individualized, person- and family-centered care planning and care coordination process.

Plans also provide enhanced care coordination for children enrolled in their general population (e.g., children who are enrolled in a MMC program by virtue of income and categorical eligibility rather than due to disability or medical need). In these cases, plans use additional steps to identify or "flag" individual CSHCN for follow-up, including analyzing plan data through specific utilization flags (e.g., emergency department utilization), standard utilization management (UM) approaches, and risk modeling and stratification. All plans also reported the importance of referrals for enhanced care coordination, including from providers familiar with a child or self-referrals from families. After identifying these children, plans may continue with defined care coordination processes (such as screenings, assessments, and care plan development), but require this initial step to identify the population of interest.

Neighborhood Health Plan of Rhode Island (NHPRI) *uses a combination of several strategies to identify children and families potentially in need of additional care coordination support, including standard UM activities, flags for inpatient hospitalizations, referrals from the member services department based on member contacts, and the use of predictive modeling algorithms to identify high-risk members. Children identified through these channels are referred to care management and then comprehensively assessed through a health risk assessment process.*

In CCHP's Care4Kids program serving children in out-of-home (foster care) placements, an initial health screen is expected to be completed within two days of a child's removal from their home in order to identify immediate needs, screen for specific mental health and developmental needs requiring immediate attention, and introduce the child and caregivers to the Care4Kids program as soon as possible. This has been part of a deliberate effort to "move care coordination activities as early as possible," at times even prior to the child's enrollment in the plan to begin connecting children to care and ensuring access to the appropriate spectrum of services.

Staff from the plans participating in the STAR Kids program in Texas noted the comprehensive nature of the Screening and Assessment Instrument (SAI) used in that program. The assessment itself can take up to three or four hours and contains multiple modules that may or may not be triggered based on the child's indicated needs identified in earlier portions of the assessment. This process also allows staff to gather information on the non-medical needs of children assessed, including information about caregivers' needs and social determinants of health (which in turn allows the plans to connect families to community-based resources and partner organizations). According to one plan, the comprehensive SAI process also allows plan staff to begin building the relationship and rapport with the family that is required for successful engagement and family-centered care coordination.

Texas plans also reported using initial health screens to preliminarily identify the needs of children prior to completion of the comprehensive SAI. Some components of the SAI must be completed by a registered nurse if those sections are required based on the child's needs, and the initial health screen can help ensure appropriate staff are assigned to complete the SAI.

Plans indicated that for some CSHCN, such as children in out-of-home placements, discontinuity in enrollment (or "churn") had limited impact since eligibility for the program was more stable than for other populations (e.g., families with income fluctuations). However, plans all reported similar activities to address breaks in enrollment where needed, such as care coordination staff working proactively with families in advance of terminations to ensure recertification, and working with families and providers following breaks in enrollment to return children to needed care.

Across the spectrum of access and coordination of care, plans reported multiple methods of connecting children

and their families to care coordination and necessary services. Plans reported that the first consideration is always ensuring the child has access to appropriate care. As a member of IEHP's staff stated, "We're always trying to figure out how to make sure the kid gets what they need," even when systems or events make it unclear how to do so. "Whenever it's grey, we take care of the kid."

Partnerships with Providers

Providers, particularly primary care physicians, are an integral partner in improving the coordination and the quality of care for vulnerable populations. CSHCN often require multiple physicians, or multiple types of clinicians, may require both physical and behavioral health (for children with chronic conditions and comorbid behavioral health diagnoses), and may require specialized providers not typically available in MMC (for example, providers of home modifications for accessibility). To address this challenge, plans expend significant effort in ensuring their provider networks are sufficiently robust, in both breadth (all required types of providers) and depth (sufficient providers to meet the needs of all enrolled members).

All plans underscored this with special emphasis on the importance of continuity of providers, whether across transitions in health care coverage (from plan to plan, or for out-of-state care), transitions in settings (out-of-home placements), or program transitions (such as in the roll-out of STAR Kids). For many children, caregivers have built relationships with physicians and other providers over the course of the child's entire lifetime, and these relationships remain important.

Staff from CCHP, for example, noted that they always prioritize continuing each child's care with the primary care physician and providers they had seen prior to removal from the home. Both California plans (HPSM and IEHP) noted the integration of plan networks with CCS program networks, ensuring that children have access to any CCS provider for all care required.

Staff from the Texas plans emphasized the importance of continuity of providers as STAR Kids implementation occurs. All three plans reported substantial plan effort in advance of the roll-out. At least one plan surveyed providers about their capacity to serve STAR Kids enrollees in the same or new ways. Plans also support significant recruitment efforts among providers not participating with the plans, including both non-traditional providers such as day providers and organizations who make home and vehicle modifications, as well as primary care and specialty physicians.

The plans reported "aggressive outreach," using state-provided data to identify providers participating in home and community-based services (HCBS) or waivers operating in certain geographic areas. In one case, a plan hired a former case manager from an adult HCBS waiver to help understand and recruit providers who could serve eligible children. On the physician side, plans offer enhanced contracts for physicians who agreed to engage in specific care coordination processes. In other cases, plans allow providers to enter into single-case agreements if he or she is willing to continue seeing their own patients but prefers to not participate more generally in Medicaid.

In many cases, children may also require the care of out-of-state specialists, particularly for extremely rare or specialized treatments. Every plan indicated that these services can easily be arranged as needed – usually through single-case agreements on an as-needed basis. The majority of the plans we spoke with operate in populous urban and suburban regions and often noted the benefits of multiple children's hospitals and Centers of Excellence readily available relatively close by. In one case (NHPRI), the plan noted that it has formal contract arrangements with out-of-state providers like Boston Children's Hospital and frequently works with providers in Massachusetts, due to the geographic proximity of the two states.

Some services may be carved out of managed care contracts, such as behavioral health services or waiver services authorized under a 1915(c) program. For children requiring carved-out services, coordination of these services still resides with the plan in order to ensure the child accesses the care required and that it is integrated into the continuum of care used by the child. This can be challenging, but plans often cite partnerships with these providers (frequently county or other public agencies) and dedicated processes intended to maximize the integration of services. CareSource, for example, has worked to develop relationships with community mental health centers, which deliver behavioral health services currently carved out of MMC (until January 1, 2018, when they will be carved in). The plan coordinates with these providers around coordination of behavioral health services, some of which are currently the responsibility of the plan (including inpatient care and prescription drugs), as well as planning ahead early for the coming carve-in.

In California, health plans are responsible for identifying and referring children to the CCS program and providing primary care and prevention services not related to the CCS-eligible medical condition. Counties with populations greater than 200,000 perform case

management CCS-care related activities for eligible children residing within their county. IEHP, for example, maintains a staff of care coordinators who specifically work hand-in-hand with the counties to oversee the complete care of the child and work collectively to identify and resolve gaps in care or supportive services. In all cases, effective coordination often hinges on timely, efficient and effective communication, with an emphasis on information sharing and communication as central components of care coordinators' work. Enhanced communication, shared records, and opportunities for shared processes all offer plans and providers robust means for improving coordination, quality, and health care outcomes.

Each of the plans described their efforts in engaging providers and promoting provider partnership in caring for this population, including efforts among both physicians as well as other types of providers. Some plans have deliberately adapted their models around existing providers or provider groups, boosted channels for communications across providers, or implemented continuing education or training programs to support physicians and build on plan-provider relationships.

NHPRI noted the transition to carve in behavioral health services as of January 1, 2016 offered an opportunity to work with providers "pretty intensively" to launch this new facet of their program. The plan reported that they "recognized [providers] were the experts" in behavioral health delivery and relied on that expertise to build the program.

The implementation of the Care4Kids approach incorporated the work of Child Advocacy Centers (CACs), which have long existed in the Wisconsin delivery system serving children in foster care. Staff at these CACs have historically and continue to conduct the initial screens for children. Plan staff indicated that the care coordination staff from the plan have proven "a huge asset" to both the CACs and the plan. These staff are co-located at the CACs, provide informational support prior to screens, and participate in a post-screen wrap-up with CAC staff and the child's caregiver, before launching into the care coordination activities occurring between the initial screening and the 30-day assessment. Other plans partner with major players in care delivery to collaborate around care coordination. HPSM works closely with Lucile Packard Children's Hospital, and the hospital staff, under contract, provide intensive case management and other specialized services, including participating in joint care coordination meetings to share approaches and lessons learned. NHPRI care coordination staff meets onsite weekly at Bradley Hospital, a major provider of inpatient mental health care to adolescents and children enrolled in the plan.

Texas Children's Health Plan (TCHP) *has plan practice managers assigned to high-volume practices in a "drug rep model" who are responsible for directly communicating and sharing information with provider practices. These are "hands-on extensions of the health plan" who come directly to the practices to share data, performance information, and other resources with the plans based on the guidance of the plan's medical affairs staff. In this way, the providers serving the largest share of enrolled children have a direct and consistent open line to the plan.*

A number of plans have employed learning collaboratives with their providers, which represents an opportunity for opening channels of communication both between the plan and providers and among provider peers. UPMC staff said the learning collaboratives offered a "third space" promoting open communication and collaboration among the participating stakeholders and partners. The plan has used learning collaborative sessions for interactive, informational or educational sessions, such as offering a presentation on the total cost of care for children in its pilot program. TCHP's Action Learning Collaborative provides a forum to share quality improvement programs and ideas, data reports, promising practices and program goals. It also offers a ready-made venue for training opportunities. CCHP reported using multiple channels to engage with providers, including statewide conferences, local grand rounds, and through a live provider support 800 number and email account. The medical directors in CCHP's Care4Kids program are practicing pediatricians familiar with the foster population and chair the foster care committee of the state chapter of the American Academy of Pediatrics (AAP). Having accessible, knowledgeable support and training builds relationships and credibility with provider partners.

While plan staff and providers' staff have different roles in care delivery and distinct perspectives on care delivery and coordination processes, plans have found

providers to be eager partners in quality improvement activities and care delivery reforms. Providers' often longstanding, close relationships with children and families offer health plans a connection to families that can strengthen care coordination activities across the health care system. In contrast, plans can offer providers information about their patients, additional support via care coordination staff, and even opportunities and support for training and practice improvement.

Plans emphasized enthusiasm among provider partners in making system improvements. For example, UPMC noted that their original pilot program among this population was well poised for success in large part because of the willing partner they found in a local, large pediatric network, Children's Community Pediatrics. In advance of the STAR Kids roll-out, TCHP noted that partners at Baylor College of Medicine were "chomping at the bit" to see what impacts could be achieved through the program and in effecting quality improvements.

Innovative Care Coordination

Care coordination is often the key to ensuring access to appropriate and adequate care for this vulnerable population. Communication and collaboration among partners, including plan staff, children and their families, primary care physicians and other providers, and other stakeholders offer ways to reduce fragmentation, gaps, or duplication in care.

Care coordination is the centerpiece of plans' efforts to support this population. As one plan staff member noted, care coordination is the "glue that holds it all together" in programs designed to serve CSHCN. Other staff noted that care coordination is the mechanism by which quality improvement and, eventually, shared savings can be achieved. Plans have implemented means for information sharing, enhanced communication, family involvement, and multi-disciplinary care planning to promote access to well-coordinated care.

The STAR Kids plans each have detailed specifications for staffing ratios for these teams in order to appropriately support the children assigned to each pod or team. For example, **Driscoll Health Plan** *employs care coordination staffing ratios ranging from 1:15 (for Level 1 members, or the highest need children) to 1:100 for Level 2 and 1:175 for Level 3 members. An entire pod, with a population of members at all level, would have an overall staffing ratio of one full-time equivalent service coordination for every 90 members. At* **Cook Children's Health Plan**, *these staffing ratios are arrayed differently: 1:30 for Level 1, 1:50 for Level 2 and 1:500 for Level 3. These staffing ratios in each plan reflect the plans' expectations around enrollment, pod assignment, and compliance with state requirements in the STAR Kids program.*

Plans are using two distinct care coordination models: a single point of contact in a named care coordinator, or a team-based model. In plans with a single point of contact, the care coordinators are still supported by additional staff, but they are the named, responsible plan staff communicating with families and members. In the team model, staff members may share some responsibilities for communicating and coordinating with families, while being supported by administrative and specialty staff (e.g., behavioral health coordination staff). In some cases, a single individual still serves as the "named" care coordinator for each enrollee.

Each of the three Texas STAR Kids plans (Cook Children's, TCHP and Driscoll) use a "pod" or team structure for their care coordination teams. Each pod has a mix of multidisciplinary care coordination staff (nurses and social workers) and administrative support staff, and serve an assigned number of members. Driscoll and TCHP assign pods a weighted mix of members at varying risk levels, while Cook Children's assigns entire pods by risk level (i.e., some pods are Level I pods, while others are made up of only Level

ll members). Each plan described additional staff or approaches supporting these teams, such as a care coordination support team phone line members can call if their team is unavailable (TCHP), transition services support staff assisting members preparing to transition to adult services (all three plans), or specialty care coordination staff focused on needs like LTSS or behavioral health services (Cook Children's).

Other plans described similar staffing arrangements. CCHP employs multidisciplinary teams for the Care4Kids program, including an intake coordinator, a health care coordinator and an outreach coordinator, who the plan describes as a "traffic control" position managing incoming and outgoing communications among all parties, including children, caregivers, and the child welfare system. HSCSN combines staff of different skill sets, background and training in care management teams of up to 15 care managers in order to allow each staff member to draw on the expertise and experience of a deep pool of care coordination staff.

The interdisciplinary teams (IDTs) at **CountyCare's** *contracted partner La Rabida Care Coordination are designed to be mobile and "meet members where they are," including in schools if necessary. These teams are assigned by site to medical home practices to ensure mobility, build relationships and rapport with providers, and become familiar with local communities and schools.* **CareSource's** *care coordination staff are regionally based, and the plan aims to hire local residents in order to ensure plan staff are familiar with community assets and strengths, build relationships in the community, and develop rapport with local health care providers.*

In other plans, a single point of contact was identified as the care coordinator (although these staff are supported by other plan staff). In plans with a strong focus on children with medically complex conditions, all or nearly all care coordinators were nurses. This was true for IEHP, HPSM, UPMC and CCP. At NHPRI and CareSource, the plans noted that the care coordinator was a named, single point of contact, but may be either a nurse or a social worker, depending on the needs of the child.

One plan operating with a single point of contact noted that they organized their care coordination deliberately to avoid overwhelming members and their families, and to assure a single point of contact for caregivers and families. In contrast, at least one plan using a team-based model noted that the team structure would be the four or five people the family got to know. This model also assured that someone was always available for the child and their family. One Texas plan (Cook Children's) noted each pod would have a parent representative, in case a family or caregiver really just needed to speak to another caregiver.

Plans also frequently mentioned both "embedding" care coordination staff at large or high-volume primary care practices and the co-location of staff who collaborate frequently on care coordination activities.

Both NHPRI and HPSM noted the intentional co-location of staff to minimize fragmentation or disconnects between care. For HPSM, the county public health nurses in the CCS program are located onsite at the plan to work as closely as possible with plan staff. For NHPRI, behavioral health and medical care coordinators are located in the same office, on the same floor, to ensure staff coordinating care for the same children are accessible to one another.

A number of plans also mentioned embedding care coordinators in primary care practices to promote collaboration between care coordination staff and providers. TCHP, for example, will embed care coordinators at its "supported practices," which are practices with a history and capacity for caring for CSHSN who have expressed an interest in taking on additional care coordination responsibilities under STAR Kids. HSCSN care coordination staff are co-located at Children's National Medical Center and its specialty clinics and have access to their scheduling system in order to make appointments for enrollees themselves. HSCSN also plans to work with individual practice groups with care coordinators already on their own staff, to collaborate with practices and share information about the plan's care coordination processes, with the goal of ensuring practice and plan staff efforts are aligned and unduplicated.

CareSource embeds care coordinators in a range of provider locations: primary care practices, federally qualified health centers (FQHCs), behavioral health clinics, and hospital-based clinics. These embedded coordinators may carry a case load of members, but can also serve as a liaison between the practice, the community, and the plan's regional staff. UPMC also employs practice-based care coordinators, and embedded coordinators are expected to leverage their location into longitudinal relationships with families and providers at the site. They also are expected to engage in more face-to-face (rather than telephonic) care coordination activities than care coordinators not based at such sites.

Multiple plans noted the important role families and caregivers play on the care coordination team. **CountyCare** *reported that the family is "part of the integrated care team," and* **Driscoll Health Plan** *emphasized the role of the family in reviewing and approving the care plan following completion of the SAI.* **Community Care Plan** *staff described families as the plan's "eyes and ears" with regard to what is going on with the child. One staff member commented, "They contact us when they have any kind of issue… whenever they need to check-in on literally anything, basically on a daily basis. They are part of the team! Almost all of them are in contact almost every single day."*

In the Care4Kids model, the intake coordinator is formally located in the CAC and is deeply involved in the processes occurring within the first few days of a child's removal from the home. The initial two-day screen is performed by a provider at the CAC, and the intake coordinator spends that brief period preceding the screen compiling any and all information available, including as much medical history as possible, information about the reasons for the child's removal from the home, and any other context. The morning of the screen, staff gather for a "huddle" in which this information is shared with the provider performing the screen, which helps each provider understand what the major concerns are before meeting with the child.

Plans underscored the importance of developing relationships with families in order to build trust and rapport. In one story reported by **UPMC,** *a mother was at risk of having her child removed from the home after failing to bring her daughter to medical appointments. Upon further exploration by the care coordinator, it was discovered that the mother was reluctant to bring the child to appointments because she felt she would be viewed as unable to care for her child. Additional care coordination and service supports for the family have resulted in the child remaining in the home and now, successfully attending school.*

All plans described the use of multiple types of staff (most frequently nurses and social workers) to best address the individual needs of each child. This was true for staffing care coordination in general but also for specific components of care coordination processes (such as relying on nurses to complete medically focused sections of the SAI in Texas) or in the use of specialty staff in special cases (such as LTSS specialists for members using LTSS at Cook Children's). Multiple plans also reported using staff in a more administrative or clerical role to assist and support the nursing and social work staff (such as CCHP, Driscoll and Cook Children's).

At CCP, the care manager is typically a nurse, as their program focuses on medically complex children, but the care manager is further supported by staff from the plan's utilization management, member services, pharmacy and other departments. CountyCare's contracted La Rabida Care Coordination teams are interdisciplinary teams including nurses, social workers, and community health workers and are assigned to specific provider sites in order to develop an "integrated care team" incorporating all partners: the interdisciplinary staff from the plan, members and their families, and health care providers.

Integration of Behavioral Health Care with Other Care

Often, behavioral health needs are a primary concern among CSHCN, including both mental health support needs as well as substance use concerns. As plans noted, family members and caregivers for these children may additionally be affected by mental health conditions or substance use disorders, which can have implications for both the child's home environment and the family's role in managing and coordinating complex care for a vulnerable child. Plans have addressed the integration and coordination of behavioral health services in unique ways to supplement routine care coordination, aiming to ensure this area of prime concern is well addressed in the continuum of care coordination.

Most plans seek to promote coordination of behavioral health services through enhanced information sharing with each child's key providers. Several plans rely on comprehensive care plans, which are shared with primary care physicians and any other providers if requested, to document all of a member's services, including key behavioral health supports. NHPRI, for example, ensures that behavioral health and medical staff share the care plans for children and adolescents receiving behavioral health care to ensure all those involved in care for the member remain on the same page.

Plans may also ensure care coordination staffing reflects the need for integrated care coordination for members with behavioral health support needs. NHPRI employs distinct behavioral health care coordination staff, but co-locates these staff alongside the rest of the care coordination team to facilitate integration. IEHP similarly co-locates behavioral health staff with care coordinators. Cook Children's assigns a behavioral health specialist to pods for Level I members to ensure integrated care management.

In a related vein, HSCSN worked to develop a mental health services site co-located with a primary care clinic in a high-need neighborhood. The approach helped to re-engage some 150 members in mental health services who had discontinued care, and dovetails with other plan efforts to deliver mental health supports in the community in the most integrated setting possible.

At least two plans (CountyCare and NHPRI) also noted the importance of changes in their states' approach to behavioral health that would offer new opportunities for coordination and collaboration. In both cases (which related to the expansion or carve-in of behavioral health services), the plans noted that this change offered

opportunities to work more closely with behavioral health providers, reduce fragmentation in care, and improve coordination. CountyCare has also adapted care coordination activities around existing programs within the state designed to support the behavioral health needs of child and adolescent members in the plan. The Crisis and Referral Entry Services (CARES) system in Illinois, which handles mental health crisis calls throughout the state and is used by all sectors in the state (e.g., schools, law enforcement, health care providers and families), dispatches mobile crisis response teams to address the child or adolescent's immediate needs, either connecting them to community-based supports or assisting in inpatient admission. CountyCare receives service logs from this system and is working to ensure that this information can easily be translated into follow-up care coordination activities for these vulnerable children and adolescents.

Supporting Non-Medical Needs of Members and Families

Non-medical needs of children and their families are often a critical influence on health care status and the success of health care programs' interventions. Children with multiple or complex medical conditions may also require support in schools, or benefit from the support of other services not covered by Medicaid, such as legal assistance, home-delivered meals, employment services, and others.

> **HSCSN** *operates a youth athletic program for member CSHCN and their siblings, and children at all levels of functioning participate as much as they can and wish to do so. The purpose of the program is to ensure that members are "out in the community" and engaged in community life and activities.*

High-quality, coordinated health care is increasingly focusing on support for the non-medical needs of the child and his or her family or social determinants of health. This emerging priority area was noted by all plans including efforts to identify, support, and coordinate around non-medical needs for all families involved in their programs. Such needs include transportation, housing, education, social services, legal support, nutrition assistance, support for caregivers, and support in developing health literacy among members and their families.

A number of plans described components of the screening or assessment processes in identifying non-medical needs of children and their families. Components of established assessment tools (such as the SAI in Texas) identify and characterize non-medical needs, with entire sections dedicated to this important area of support. Plans also identify such needs through direct requests from families or caregivers and through direct referrals or requests from providers serving families.

One plan (NHPRI) noted the importance of using different opportunities to identify medical as well as non-medical needs; they work with families during an inpatient admission to learn more from the family about the events that led to the admission and what supports could assist them in avoiding similar hospitalizations in the future.

Virtually all plans emphasized the need for relationship-building with families as the foundation to successfully learning about and addressing social determinants, noting that families are unlikely to share all of their challenges on the first day they meet with a care coordinator.

Once needs have been identified, plans have a number of different approaches to meet those needs. Virtually all plans described dedicated staff or resource lists of

Staff at **CountyCare** *reported that ongoing relationship-building between care coordination staff at their partner, La Rabida Care Coordination, and their enrolled members' families promoted novel engagement and support offered to families. In one case, a mother was unable to attend her child's IEP meeting due to her work schedule. The mother asked the school and the plan whether her child's care coordinator could attend as her proxy and as her child's advocate, and all parties agreed. This allowed the IEP process to move forward, allowed the care coordinator even more insight into the other support needs of the child, and offered the family supported where most needed.*

community-based partner organizations who could meet identified needs (e.g., legal assistance organizations or programs such as Meals on Wheels).

Plans often work collaboratively with community partners, often linking them with care coordination staff to build relationships, improve care coordination staff awareness of partners, and educate those partners about plan activities. At one Texas plan (TCHP), the parent of a child with special needs who was deeply familiar with the community supports available created a resource guide for members and families. Plan staff noted that this not only helped the plan deepen its knowledge of the services available, but also provided additional rapport with parents as she was so familiar with their experiences. Other plans reported hiring individuals previously working at community partner organizations to bring in "on-the-ground" perspective and knowledge. Plans often also engage with other public partners to ensure sharing of information, best practice approaches, and coordination of efforts. This could mean working with schools or other public programs, but is most apparent in coordination with child welfare agencies in regard to children in out-of-home. NHPRI staff, for example, meet with staff from the child welfare agency on a monthly basis and engage directly in care coordination planning with the agency, particularly for children returning from out-of-state placements (e.g., in a psychiatric residential treatment facility).

Plans mentioned additional services they cover to support the children and their families. A few plans, including IEHP and HSCSN, offer respite services to assist caregivers in the challenging, non-stop effort of caring for a child with complex needs. Caregiver support is delivered in other ways, as well; some plans described offering specific informational or educational support to parents and caregivers to help them advocate for their child in other areas (most often at schools with special education programs and in Individualized Education Plan (IEP) meetings). CCHP program staff noted that the early care coordination activities (in particular, the initial screening and the documentation provided to the physician performing the 30-day assessment) allowed them to provide caregivers information, advice and feedback on the child's care needs and how new foster parents can best support each child. Another plan (Driscoll) noted that part of care coordination activities with families was helping families learn to advocate for the child in school and within special education programs.

Finally, a few plans indicated that they viewed support for family and caregivers' needs as directly tied to supporting the ongoing well-being of the child. Staff from CountyCare noted that behavioral health needs of caregivers or family members can have significant impacts on children's health status and ongoing health

Care coordination activities can uncover non-medical needs with a significant impact on the success of health care interventions. **HSCSN** *described an enrollee with sickle cell disease with dozens of emergency department visits in just a short three-month span. Upon closer assessment, the plan learned the young woman was homeless and seeking care in the ED in order to find shelter. The plan connected the enrollee with community-based supports to provide temporary housing assistance, which offered the opportunity to stabilize her health condition while the team works to secure long-term housing.*

care. In response, the plan has considered potential innovations in this area such as enrolling the family member in enhanced care coordination activities to shore up supports for the already-enrolled child. These types of medical home approaches seek to work with the child holistically, which can mean working with the whole family to ensure needs are met.

This role in supporting families is crucial. One service coordinator at Driscoll, a parent of a CSHCN, related how as a single parent, in school full-time, it was often incredibly challenging coordinating specialist and therapy appointments for her daughter. She noted that "if I had had someone, one person, there to cheer me on and guide me as to programs that were available or how to maneuver through the school system," things could have been easier. Now, she says, "I am that person. I am here to cheer the members on. I am here to make sure that they are utilizing every possible avenue. I am here to offer these children and their families hope."

Effective Data Mining and Analysis

In an era of "big data," there is more opportunity to use information to improve access and quality of care. CSHCN represent a population who are likely to benefit from these innovations including analysis of claims data reflecting high levels and broad spectrum of service use, sharing of assessment and care management system data, and using electronic health records to identify gaps in care, opportunities for enhanced care management, and to assess quality of care and care processes. In some cases, data from multiple sources can be combined to offer an even more complete picture of care.

Safety net health plans are using data in many ways to support their programs for CSHCN. As noted in a prior section, some plans use predictive modeling and risk stratification approaches with their claims data to identify children in need of enhanced care coordination. Plans are also using claims data to supplement assessment and care coordination processes to identify gaps in care, particularly well visits or preventive care. Plans also noted the use of such data to flag events for follow-up care coordination activities.

NHPRI uses an advanced risk modeling program (the Milliman Advanced Risk Adjustment or MARA program) to identify high-risk members in their larger pediatric population who may benefit from enhanced care coordination activities. This system currently relies on claims data, but the plan hopes to move toward using a combination of the risk scores output by this model and data from the plan's health risk assessments. TCHP also described risk modeling used to identify high-risk members for follow-up. The program, called IMPACT Pro, assesses service use (particularly inpatient, outpatient, and pharmacy claims), diagnoses, and costs. The risk score output by the program will take into account current services as well as the historical three years' worth of data provided by the state at new member enrollment. Texas provided an initial stratification of STAR Kids enrollees using a program developed by 3M and historic claims data from the state's fee-for-service coverage of this population. The STAR Kids plans rely on this initial stratification to proceed with care coordination activities, although assessment and other plan data may eventually identify the need to reassign members to different levels. HPSM reported being in the initial stages of exploring risk stratification to assist targeting of care coordination efforts.

In other cases, claims data are being used to identify high-need members, high users of services, or other good candidates for follow up. UPMC, for example, used claims data to identify appropriate candidates for its initial pilot program, using total cost of care as a proxy for medical complexity.

Beyond identification of children in need of care coordination activities, plans are using data in novel ways to identify specific needs and gaps. CCP analyzes its claims data to identify children without routine preventive visits, including dental visits, and translates these data into a texting campaign to prompt families to seek care. The caregiver for a child missing a visit will receive a text with the notification that the child is due for a visit along with a link to a "microsite" with more information about what the visit is for and the benefits of making the trip to the clinician's office. CountyCare uses an innovative web-based tool pioneered by its partner Medical Home Network to flag hospital visits for care coordination follow-up. The tool is linked to local hospital registration systems and alerts care managers in real time about members' emergency department visits or inpatient admissions. IEHP receives and reviews data on service authorizations within the CCS program to facilitate plan coordination around those (carved out) services, and CareSource has access to hospital admission, transfer and discharge data through a statewide information exchange that covers a large share of the state, which it can use to coordinate care for members with inpatient visits.

Plans share information from these and other data mining efforts with providers, families, and other partners in various ways. This involves sharing information with

"high-volume" providers about who may have gaps in care or other services they need; providing additional information to the care coordination team to make them aware of the child's full spectrum of care; and using "data dashboards" available to multiple stakeholders to quickly segment and understand the data.

A number of plans reported sharing data with high-volume providers or provider agencies. CCP provides primary care physicians with a list of children due for routine preventive care visits prior to each month. Driscoll creates primary care physician profiles covering information about rates of well-child visits, immunizations and other common metrics on a semiannual basis and physically takes them to the physician practices to review them. UPMC coordinates on carved-out behavioral health services by sharing information with contracted county behavioral health agencies, including granting them access to a portal into the plan's care coordination system.

CountyCare uses a quality metrics dashboard showing standard measures of care, which can be "segmented" to show individual providers or care coordinators their slice of the plan's population. Driscoll similarly has a portal that shows primary care physicians likely gaps in care where rates on key targets like immunizations are lower than expected. CareSource's care management system delivers data to a provider portal where physicians and other providers can see care management messages, gaps in members' care, and more. UPMC created "member profiles" for every child enrolled in the pilot, based on claims data, which could be shared with providers and the care coordination team to view the child's entire picture at once.

The use of data is not without its challenges. Multiple plans cited challenges to integrating multiple data sources to make the data more effective. One plan noted the different drawbacks of multiple data sources, including some information that is not available in claims or other administrative data, but are based on self-report. In some cases, the plan may not have all of the data – this is true for any child for whom Medicaid is the secondary insurer, and in programs like CCS, where the claims are the responsibility of the state and not available to the plans. Despite that, plans are directing substantial attention to this area and identifying opportunities for innovation.

Measuring Quality of Care and Investing In Quality Improvement

Measurement of access and quality of care among this population can be challenging in many respects. Since the broad term CSHCN incorporates an array of populations that includes children with common, treatable chronic physical or mental health conditions as well as children with complex medical conditions or children who are medically fragile, measurement of care delivery and care outcomes is extremely complex. In addition, rare diagnoses and complex combinations of comorbidities may result in very small populations for assessing key condition-specific processes and outcomes for these children. Even among children with common chronic diseases like diabetes, the population often is not large enough to smooth out the volatility of individual outliers in data.

As a result, measurement among this population often trends toward measuring outcomes and events that are common to a larger population of all children. Further, in many plans, CSHCN are also enrolled in the general, larger MMC populations and assessment of their care is included in overall plan performance rates.

While virtually all plans referenced HEDIS reporting or mentioned similar reporting mechanisms to assess access and quality of care, at least one plan mentioned the value of reporting these standard metrics specifically for CSHCN. Families of children with special needs are often stretched so thin with appointments for specialty care and condition-specific services they may miss primary care appointments or dental appointments. Standard measures of preventive care offer an opportunity to assess primary care required by all children within the program or population, regardless of diagnosis or additional service needs. Similarly, tracking utilization of certain services (such as average length of stay in inpatient admissions, inpatient admissions or emergency department visits) can be used across a broad population, yet still offer insight into the quality of care for CSHCN.

Most plans also noted reporting requirements on care coordination processes specifically for this high-touch population. In some cases, plans tracked care coordination milestones for internal purposes (e.g., number of telephonic contacts per member), while in others, such tracking was mandated by the state or program (e.g., STAR Kids). In some cases, plans also reported tracking and reporting data on measures beyond these measures as well.

Care4Kids Quality Measures Overview

- Timely Out of Home Care Health Screen
- Timely Mental Health and/or Developmental Health Screen
- Timely Comprehensive Initial Health Assessment
- Blood Lead Testing (BLS, HEDIS 2014)
- Timely Developmental Assessment
- Timely Mental Health Assessment
- Timely Comprehensive Health Care Plan
- Enhanced Health Check periodicity compliance
- Timely Comprehensive Dental Exams
- Childhood and Adolescent Immunization Status (HEDIS)
- Outpatient Mental Health Follow Up (HEDIS)
- Emergency Department Utilization (HEDIS)
- Inpatient Hospital Utilization (HEDIS)
- Anti-Psychotic Medication (HEDIS)
- Polypharmacy

With regard to care coordination, plans are tracking completion and timing of initial screens, assessments, and completion of or updates to comprehensive care plans. Some plans, like HPSM, track timeframes for referrals to specialty care or, like CCP, regular and frequent meetings of the multidisciplinary care team. HSCSN noted that its care coordination tracking report encompasses some 50 measures covering a range of care coordination processes.

A few plans noted that the volume and frequency of reporting could be a challenge but that it was an indicator of the level of interest in the success of the program. Plans also noted that some of these process measures required the use of multiple, usually unlinked, data sources, which creates other challenges.

A few plans also cited measures and reports examining more specific metrics of special interest to this population. Care4Kids employs a polypharmacy measure which assesses the number of enrolled children meeting the polypharmacy definition (four or more psychotropic medications over a three-month consecutive enrollment period) who have received a comprehensive polypharmacy interdisciplinary case review. Cook Children's similarly examines the use of antipsychotics and metabolic after-effects of these drugs given the prevalence of mental health needs among the population. UPMC produces and reviews two reports on lead risks, one identifying screening gaps among children in high-lead areas and another which is an environmental assessment.

Measures of satisfaction with care and quality of life can be especially important indicators of quality of care; for children and families interacting with diffuse and fragmented services, satisfaction with care can be a high bar. According to 2016 NCQA Quality Compass reports, 83.22% of all children with complex care needs are happy with their care in their health plan (i.e., rated it 8, 9, or 10), benchmarked at the 50th percentile of responses related to all lines of coverage business. Other quality of life indicators can serve as a proxy for understanding children's and families' engagement in their care and the success of their care. Staff at one plan suggested, for example, using absenteeism from school as a useful indicator in this regard. If children are spending less time in inpatient care or less time sick, they spend more time in school and engaged in the community.

Beyond measurement of the quality of ongoing care, plans are engaged in an array of innovative quality improvement initiatives. In addition to instituting incentives for practice improvement (e.g., for medical home model implementation), plans are examining and addressing issues from access to social determinants impacting the success of health care interventions for this population. For example, UPMC is using geocoded data to map dentists in relation to primary care physicians participating in the plan. From this research, the plan hopes to develop a "dental home" model with support from the state. The plan also hopes to host meet-and-greet opportunities for primary care physicians to build relationships with local dentists to better identify where available dentists are able to provide care to their population.

Cook Children's operates a "Healthy Homes" project involving children with asthma who have had more than three emergency department visits in the past year. For each child and family, the project completes a home assessment to identify asthma triggers, sometimes changing rugs, air filters, providing advice about smoking in the home, and addressing insect problems. CareSource operates a similar pilot in Cuyahoga County among children with asthma who have multiple hospital visits; the plan can intervene with home remediation of asthma triggers. Both plans' programs are in early

stages, but the plans are optimistic about initial data and the likely return on this preventive investment.

Innovative Payment Models

Ongoing initiatives at the federal and state levels towards value-based purchasing, pay-for-performance and pay-for-quality approaches have driven interest in these options nationwide. Linking payment incentives to process and outcome measures and performance of health care delivery offers payers an opportunity for greater accountability and a driver of key components of comprehensive care, such as well visits. Innovative payment approaches also offer payers new approaches to finance services or supports not typically reimbursed under traditional fee-for-service payment models, such as care coordination staff.

Plans reported employing a variety of innovative delivery arrangements, payment models, and incentive programs, ranging from partnerships with accountable care organizations (ACOs), shared savings programs, pay-for-quality and pay-for-performance incentive programs and incentives for implementation of enhanced care coordination.

Pay-for-quality arrangements were common and driven by performance on commonly accepted markers of access and quality (such as rates of well child visits or other standard measures). Often these arrangements are not specific to CSHCN, but do not exclude this population from reporting and payment incentives. A smaller number of plans also reported shared savings arrangements with providers, some noting that these also incorporated shared risk (or would in the future). In addition to specified thresholds for savings, these arrangements also involved requiring that providers maintain or improve performance on specific measures (such as designated HEDIS items). These arrangements were also typically not limited to the CSHCN population.

Both Driscoll and TCHP mentioned gainsharing with providers on total cost of care savings beyond three percent, pending performance on identified measures. UPMC also described a shared savings program with a large pediatric provider, Children's Community Pediatrics, tied to HEDIS measure performance. CCP and IEHP also reported using pay-for-quality or other arrangements generally tied to HEDIS or other standard measures, but that these were implemented plan-wide and not specific to CSHCN.

Several plans, including Cook Children's and NHPRI, made specific mention of support and incentives offered to physician practices to become medical home models. Plans also reported incentive payments for providers to finance and promote engagement in the care coordination process, and emphasized that improved care coordination was the mechanism they believed would drive shared savings in the health care delivery arrangement. Driscoll, for example, recontracted with all of its primary care physicians in advance of STAR Kids implementation to incentivize development of medical home models and to reimburse physicians for their role in care plan development. UPMC used foundation support from the Robert Wood Johnson Foundation (RWJF) to pilot its care coordination model among CSHCN. The program paid for staff time to facilitate and improve care coordination activities among some of the highest-need CSHCN in the plan, and found a return on investment of $3.19—a program-attributable savings of $1.77 million over two years.

At **CareSource,** *nearly 50 percent of members are served by providers engaged in some form of value-based purchasing arrangements, and these arrangements are in operation for all different types of providers—hospitals, FQHCs, and independent physician practices.*

A small number of plans reported efforts and investment in novel delivery arrangements, such as ACOs or new capitated arrangements with providers. Some plans made note of the fact that their plan was owned by an integrated health care provider organization (such as a children's hospital system). For example, Driscoll noted that primary care physicians can opt to participate in a capitated arrangement instead of the enhanced fee-for-service contract. CountyCare recently began contracting with a behavioral health provider on a capitated basis for the first time. This provider will actually be the state's pilot site for the soon-to-be-implemented Illinois Medicaid Child and Adolescent Needs and Strengths (IM-CANS), part of major behavioral health reforms coming in Illinois. While a number of plans mentioned exploring risk-sharing models for their providers, most also noted that in some cases the prospect was "scary" for some providers unused to such arrangements or encountering them for the first time.

Common Challenges and Looking Ahead

Plans offered several insights into common challenges that they face in serving this complex population of children and adolescents. Access to and quality of information or data was cited as a major challenge by several plans. These challenges include some simple barriers such as missing or incorrect phone numbers for families, making initial outreach difficult. Other plans noted that Medicaid's role as a secondary insurer for some children in this population means that claims and other data were incomplete in regard to the child's total array of services and care.

Other challenges are more complex. Several plans noted the challenge of impacting outcomes for a complex population when some children are enrolled in their plans for comparatively short periods of time. Changes in a state's delivery system, such as implementation of large new programs, can require major shifts to existing plan processes and programs. Important partners in care may be conspicuously absent, such as parents and families for children in out-of-home care, or partners may be diffuse and difficult to coordinate. Finally, the social determinants of health, poverty and income disparity, and other structural or social phenomena were noted as challenges over which the plan can exert little influence. Ultimately, plans have to determine where to best focus their efforts.

Despite these challenges, plans showed great enthusiasm for what lies ahead. Multiple plans are exploring geographic or other expansions, and plans described other opportunities they expect to leverage in the coming years. One plan noted that increased access to multiple types of data would allow for improved reporting and research on racial, ethnic, and language disparities at the plan level, previously limited by the poor quality of these data in Medicaid-supplied data. Other plans spoke about initiatives to partner with vendors in new ways to promote chronic disease management among members, opportunities for enhanced care coordination under changes in the Medicaid delivery system, and ways to translate newly published research into enhanced supports for CSHCN.

The three Texas plans, interviewed on the cusp of the STAR Kids program implementation, were particularly optimistic about what the future holds. The three plans spoke similarly about the "huge leap" that STAR Kids represents, and how the "transformative nature" of the program, if successful, will allow them to positively influence the way care is provided for this population all across the U.S.

Conclusion

ACAP member health plans are playing an increasingly important role in facilitating coordinated care for children with complex health care needs, using innovative approaches to identify potentially vulnerable enrollees, provide targeted resources to patients, their families and caregivers and provider teams, and bridge multiple service systems for this population and their families.

In this report, we have highlighted a range of these practices. Plans have deployed strategies such as predictive modeling; comprehensive assessment tools; colocation and embedding of care coordination staff; unique and diverse care coordination staffing approaches; expanded communication with providers via learning collaboratives and grand rounds; novel outreach to families, such as through texting campaigns; value-based purchasing and shared savings programs; and innovative quality improvement programs.

The ultimate goal of these efforts is to assure that CSHN receive the highest quality care including access to a broad range of primary and specialty services. Safety net health plans are proud innovators of these approaches and continue to develop and implement new ideas in order to improve care coordination, access and quality for these children and their families and caregivers. Through innovations like these, plans can transform care for our most vulnerable populations and offer an example for high quality Medicaid delivery systems across the nation.

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Appendix

Discussion Topics

Effective pathways for access to care and care coordination for children with medically complex conditions

a. How are children referred to or enrolled in your program?
b. How do you define your population of children with special health care needs or medically complex children?
c. What is the primary focus of services under your model?
d. Under what Medicaid authority is this program operating?
e. What are the geographic parameters of the program (statewide, county, multi-state)?
f. What is the first step in the care planning and care coordination process? How do you identify the care coordination needs of enrolled children?

Innovative care coordination models, including at provider sites, and effective models for care management staffing

a. Who is primarily responsible for management and oversight of each child's care coordination activities?
b. What happens when kids churn both in or out of the plan? Is this viewed as a substantial problem for your program and your care delivery or coordination efforts, or not?
c. Given the complexity and diversity of care needs among your enrollees, what mechanisms have you found most successful in identifying health care needs and ensuring access to the most appropriate spectrum of care for each child?

Integration of behavioral health care, managed long term services and supports, and other services

a. What successful strategies have you used to identify a child's needs for, and then integrate into the child's care delivery, specialty services such as behavioral health, long term services and supports, or any other specialized services?
b. Are there innovative technologies or processes that you use to facilitate coordination and integration of care?
c. Are there any "lessons learned" from your experience in integrating diverse health care services care for this population?

Supports for non-medical needs (social determinants of health), including supports for caregivers

a. What strategies have you used to identify the most pressing non-medical needs of children enrolled, including supports for their caregivers?

Innovative partnerships with child-focused providers, including children's hospitals, and inclusion in provider networks of child-focused providers operating across state lines

a. What approaches have worked best in your efforts to initiate, develop and maintain your relationships with your providers, particularly child-focused providers such as children's hospitals?
b. How have your relationships with providers and provider groups evolved over time?
c. Do you have any "lessons learned" from your experiences contracting with any types of providers, including specialists or specialty/children's hospitals?
d. How, if at all, do you work with out-of-state providers to ensure your children and families have access to comprehensive and appropriate care?

Value-based purchasing or other innovative payment models for children with complex health care needs, including potential Medicaid savings resulting from the program

a. Have you implemented any value-based purchasing arrangements or other innovative payment models, including pay for performance, with your providers? If so, can you tell us a little bit about the process of doing so, from stakeholder / provider engagement to roll-out?

b. Have these innovative efforts resulted in savings or quality improvements in the Medicaid program? Can you share examples?

Effective data mining related to identification of children with special health care needs for care coordination and special programs

a. Are there innovative ways you use data you have in-house or provided by Medicaid to identify children to enroll, identify care needs, monitor care delivery, quality of care, or outcomes?

Effective models for measuring and improving quality of care for children with medically complex conditions

a. What are some of the specific measures you have successfully used to examine quality of care or health outcomes for this special population of children, and how are these calculated?
b. Do you share quality of care or quality improvement measure data with providers or other stakeholders? Is this information used in any ways other than to monitor your program (e.g., bonus payments)?

Final Questions

a. What is the greatest challenge with your program?
b. What is on the horizon for your program, whether changes to the program or challenges you foresee coming down the road?

Endnotes

1 ACAP, 2015
2 "The Population Of CSHCN." *CSHCN Population, NS-CSHCN Chartbook 2009–2010*. Maternal and Child Health Bureau, n.d. Retrieved from: http://mchb.hrsa.gov/cshcn0910/population/cp.html
3 Cohen, E., D. Z. Kuo, R. Agrawal, J. G. Berry, S. K. M. Bhagat, T. D. Simon, and R. Srivastava. (2011). "Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives." Pediatrics 127.3: 529–38. Retrieved from: http://pediatrics.aappublications.org/content/127/3/529
4 Anderson, L. S. "Mothers of Children with Special Health Care Needs: Documenting the Experience of Their Children's Care in the School Setting." The Journal of School Nursing 25.5 (2009): 342-51. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2764271/
5 Association for Community Affiliated Plans (ACAP). (February 2015). Innovation Care Coordination Strategies: Four Initiatives of Safety Net Health Plans. Retrieved from: http://www.communityplans.net/Portals/0/Fact%20Sheets/Innovative%20SNHP%20Care%20Coordination%20Strategies.pdf.
6 ACAP, 2015
7 "Prevalence of CSHCN: Individuals And Households." Prevalence of CSHCN: Individuals and Households, NS-CSHCN Chartbook 2009–2010. Maternal and Child Health Bureau, n.d. Retrieved from: http://mchb.hrsa.gov/cshcn0910/population/pages/pc/pcih.html
8 Cohen, 2011
9 Cohen, 2011
10 Centers for Disease Control and Prevention (2013). Mental Health Surveillance Among Children—United States, 2005–2011. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/su6202a1.htm
11 Child and Adolescent Health Measurement Initiative (2012). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved from: http://www.childhealthdata.org/learn/NS-CSHCN
12 Center for Advancing Health Policy and Practice (2013). Fact Sheet: Medicaid and CSHCN/Disabilities. Retrieved from: http://cahpp.org/resources/fact-sheet-medicaid-and-children-with-special-health-care-needsdisabilities-an-overview/
13 Wietecha, Mark. (December 2014). "Evolving Medicaid To Better Serve Children With Medically Complex Conditions." *Health Affairs*. Retrieved from: http://healthaffairs.org/blog/2014/12/08/evolving-medicaid-to-better-serve-children-with-medically-complex-conditions/
14 NS-CSHCN Chartbook 2009–2010, 2013
15 Karpook, J. & Werner, M. (2016). Five Keys to Success: Advancing Care Models for Children with Complex Medical Needs. The Chartis Group. Retrieved from: http://www.chartis.com/resources/files/Advancing-Care-Models-for-Children-with-Complex-Medical-Needs-Final-indd.pdf.
16 Berry, J. G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., ... & Feudtner, C. (2014). Children with medical complexity and Medicaid: spending and cost savings. Health Affairs, 33(12), 2199–2206. Retrieved from: http://archpedi.jamanetwork.com/article.aspx?articleid=1107633.
17 Cohen, 2011
18 Berry, Jay G (2015). What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System. Issue brief. Division of General Pediatrics, Department of Medicine, Boston Children's Hospital, Harvard Medical School. Palo Alto: Lucile Packard Foundation for Children's Health,. Retrieved from: http://www.lpfch.org/publication/what-children-medical-complexity-their-families-and-healthcare-providers-deserve-ideal
19 Anderson, 2009
20 ACAP, 2015
21 Connecticut Birth to Three System (September 2007). Service Guideline 7: Children with Complex Medical Needs. Retrieved from: http://www.birth23.org/files/SGsPlus/SG7-CompMed.pdf.
22 Vestal, C. (January 2015). Improving Medicaid for 'Medically Complex' Kids. The PEW Charitable Trusts. Retrieved from: http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/1/08/improving-medicaid-for-medically-complex-kids.
23 Rudowitz, R., Artiga, S., & Arguello, R. (May 2014). Children's Health Coverage: Medicaid, CHIP, and the ACA. The Henry J. Kaiser Family Foundation. Retrieved from: http://kff.org/health-reform/issue-brief/childrens-health-coverage-medicaid-chip-and-the-aca/.
24 NS-CSHCN Chartbook 2009–2010, 2013
25 Karpook and Werner, 2016
26 Simon, T. D., Berry, J., Feudtner, C., Stone, B. L., Sheng, X., Bratton, S. L., ... & Srivastava, R. (2010). Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics, 126(4), 647–655.
27 Kuo, D., Cohen, E., Agrawal, R., Berry, J., & Casey, P. A National Profile of Caregiver Challenges of More-Complex Children with Special Health Care Needs. JAMA Pediatrics. Nov. 2011: 165 (11).
28 "Health First Colorado Buy-in Program for Children with Disabilities." Colorado Department of Health Care Policy & Financing. State of Colorado. Retrieved from: https://www.colorado.gov/pacific/hcpf/medicaid-buy-program-children-disabilities
29 "Links to Integrate and Coordinate Services for Children and Youth With Special Health Care Needs". Great LINCS. Washington State Department of Health. Retrieved from: http://medicalhome.org/wp-content/uploads/2015/06/GreatLincsFactSheetNW.pdf
30 Lovejoy, 2015
31 "Care Coordination." Children's Special Health Care Services (CSHCS). Indiana State Department of Health. Retrieved from: http://www.in.gov/isdh/19613.htm
32 ACAP, 2015
33 "Managed Care." Medicaid. Centers for Medicare and Medicaid Services. Retrieved from: https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/managed-care/managed-care-site.html
34 Silow-Carroll, S., Brodsky, K., Rodin, D., Melia, A., & Sanchez, M. (February 2016). Access to Care for Children with Special Health Care Needs: The Role of Medicaid Managed Care Contracts: Final Report to the Medicaid and CHIP Payment and Access Commission. Urban Institute. Retrieved from: https://www.macpac.gov/wp-content/uploads/2016/02/managed-care-contracts-access-for-children-with-special-needs.pdf.
35 Smith, V.K., Gifford, K., Ellis, E., Edwards, B., Rudowitz, R., Hinton, E.,...& Valentine, A. (October 2016). Implementing Coverage and Payment Initiatives: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2016 and 2017. Kaiser Family Foundation. Retrieved from: http://files.kff.org/attachment/Report-Implementing-Coverage-and-Payment-Initiatives
36 ACAP, 2015
37 Berry, 2014
38 Oehlmann, M. (2004). Improving Managed Care for Children with Special Needs: A Best Clinical and Administrative Practices Toolkit. Center for Health Care Strategies. Retrieved from: http://www.chcs.org/media/CSHCN_Toolkit.pdf.
39 Rosenthal, Jill, Mary Henderson, Jennifer Dolatshahi, Catherine Hess, Carol Tobias, Sara Bachman, and Meg Comeau. Public Insurance Programs and Children with Special Health Care Needs. Rep. National Academy for State Health Policy. N.p.: Catalyst Center, 2012. Retrieved from: http://www.nashp.org/sites/default/files/Medicaid_101_tutorial.pdf
40 O'Malley Watts, Molly, Elizabeth Cornachione, and Marybeth Musumeci. "Medicaid Financial Eligibility for Seniors and People with Disabilities In 2015 – Report." Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015 – Report – 8843. N.p., 1 Mar. 2016. Retrieved from: http://kff.org/medicaid/report/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015/
41 Rosenthal et al., 2012
42 https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html
43 Raphael, Jean, Matthew Sadof, Christopher Stille, Sara Toomey, and David Keller. "Not Just Little Adults: Considerations for Quality Measures of Child Health Care." Agency for Health Care Research and Quality. U.S Department for Health and Human Services, 7 Apr. 2014. Retrieved from: https://www.qualitymeasures.ahrq.gov/expert/expert-commentary/47906/not-just-little-adults-considerations-for-quality-measures-of-child-health-care
44 Raphael et al., 2014
45 Silow-Carroll et al., 2016
46 ACAP, 2015

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