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Developing Structure and Process Standards for Systems of Care Serving Children and Youth with Special Health Care Needs

A White Paper from the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Lucile Packard Foundation for Children's Health

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About AMCHP

The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. AMCHP members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community-based family health professionals, as well as families themselves.

About the Foundation

The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation is a public charity, founded in 1997.

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Background

Children and youth with special health care needs (CYSHCN) are a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 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.[1] In a recent national survey, children with a chronic condition birth to age 18 represented approximately 15 percent of the entire child population in the United States.[2]

Children and youth with special health care needs and their families typically receive services and supports from multiple systems – health care, public health, education, mental health, social services, and respite to name a few. Within any one of these systems, CYSHCN may be served by multiple providers and community-based systems. There is no doubt that the need for services and supports among CYSHCN presents significant challenges for developing comprehensive systems of care among health care and other child-serving systems.

For more than three decades, numerous national reports, initiatives, and research studies have described or called for frameworks, standards and various measures to advance a comprehensive system of care for CYSHCN and their families. Efforts in the mid-1980s, led by Surgeon General C. Everett Koop, called for a national agenda to "develop strategies for comprehensive services needed by children with special health care needs, address the challenges and burdens of the families of these children, and stimulate community resources."[3] Since that time, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) adopted and led federal efforts to focus on the following six system outcome areas tied to national performance measures for CYSHCN: 1) families as partners, 2) medical homes, 3) financing of care for needed services, 4) coordinated services, 5) early and continuous screening, and 6) effective transition to adult health care.[4] Each of these outcome areas also are incorporated as objectives within Healthy People 2020 and the President's New Freedom Initiative.[5] Process and structural standards and measures relevant to systems of care serving CYSHCN also are included in National Committee for Quality Assurance (NCQA) quality standards for health plans and provider groups,[6] Children's Health Insurance Program Reauthorization Act (CHIPRA) Quality Measures,[7] Title V Maternal and Child Health (MCH) Services Block Grant Performance Measures,[8] and the model Pediatric Managed Care Contracting Purchasing Specifications developed by the George Washington University.[9]

These and other efforts have helped to establish important efforts in states, communities, health plans, provider practices, and other areas to build comprehensive systems of care for CYSHCN. However, they have not resulted in an agreed on, nationally endorsed set of standards that could be used and applied within health care and public health systems and other child-serving systems to improve health care quality and health outcomes for this population of children. Furthermore, many of these frameworks and tools were developed prior to the passage of the *Patient Protection and Affordable Care Act* (ACA) and other significant health system reforms that are currently underway across the country. Achieving consensus on the necessary capacity and performance of systems serving CYSHCN is essential to achieving comprehensive, quality systems of care for this population of children.

About the Project

The overall goal of phase one of the project, *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs*, is to compile, define, and reach consensus among a diverse group of stakeholders on the necessary process and structural standards for health care systems serving CYSHCN. Creating a comprehensive, quality system of care for CYSHCN has been one of the most challenging areas for state health leaders and other stakeholders such as state Title V maternal and child health programs, pediatricians and family physicians, health plans, state Medicaid and Children's Health Insurance Program (CHIP) agencies, and families. The ACA has further heightened this need as states prepare to extend coverage to millions of uninsured children and adults, design essential health benefits, and implement new provisions to achieve the "Triple Aim" of: 1) improving the patient experience of care (including quality and satisfaction), 2) improving the health of populations, and 3) reducing or bending the curve of health care costs.[1]

The products and efforts from the first phase of this project are the following:

1. This background white paper highlighting findings from the project research
2. Case studies highlighting promising state practices in developing and implementing system standards of care for CYSHCN
3. Convening of a national work group to guide and reach consensus on the desired capacity and performance of systems of care serving CYSHCN
4. Development of a core set of national system standards that was guided, informed, and endorsed by key stakeholders at the national level and state level

This white paper compiles the extant research on desired capacity and performance of systems of care serving CYSHCN, summarizes input from key stakeholders as to the recommended focus of this work, and includes case studies of four sites that are using system standards in their work with children and youth with special health care needs. It was initially prepared as a background paper to serve as a basis for discussion, exchange and consensus on a core set of structure and process standards by the project's national work group. Further information about the project methodology, including information about the national work group, can be found in the next section. Finally, the structure and process standards that were developed by the project with guidance and input from the national work group are contained in a separate companion document to this background white paper.

Berwick DM, Nolan TW, Whittington J. Thetriple aim: care, health, and cost. Health Aff. 2008;27(3):759–769

Project Methodology

The products from this project, particularly the national system standards, were developed using a comprehensive, multipronged approach involving an extensive literature review, key informant interviews, case studies of four sites that are using system standards, and the guidance and input from the national work group of diverse stakeholders. Information about the activities completed to accomplish this work follows.

Literature Review

A comprehensive literature review of national reports, standards and frameworks, and research related to the necessary capacity and performance of systems of care serving CYSHCN was conducted. Materials reviewed covered areas including core components (e.g., medical home, care coordination) of systems of care for CYSHCN, health care reform, quality measures, and federal statutory guidance. Findings from the literature review were used to inform the overall approach and implementation of the project, guide selection and questions of key informants, and inform the focus of case studies and content of the system standards.

With regard to system standards, AMCHP synthesized existing standards from the literature and created draft standards in areas where there were no standards but clear consensus on a core system component or issue. The synthesis of this work was summarized and served as the foundation of the national work group discussions, review and development of system standards.

Key Informant Interviews

Structured telephone interviews were conducted early in the project with more than 30 national, state, and local stakeholders representing state Title V CYSHCN programs and Medicaid agencies, family advocates, provider groups, health plans, health services researchers, children's hospitals, federal agencies, and others. The purpose of the interviews was to obtain guidance on the project goals, factors necessary for improving systems of care for CYSHCN in today's health care environment, the role of system standards, recruitment of work group membership, and considerations for obtaining national consensus on system standards for CYSHCN. The key themes, findings and recommendations from these interviews are included in this white paper and formed the starting point for the national work group efforts (A list of the key informants can be found in Appendix A.)

Case Studies

To identify the case study states, AMCHP used a multipronged approach involving a 50-state survey, key informant input, qualitative information gathering and analysis, and phone interviews. First, AMCHP surveyed state Title V CYSHCN directors in the 50 states to identify states and other entities that might be using comprehensive system standards in their state Title V CYSHCN program, Medicaid agency and/or health plan. Second, key informants were asked whether they were aware of any model structure and process standards for CYSHCN that were being used. Ten states and two child-only Medicaid health plans were identified for potential case study: Colorado, Florida, Iowa, Michigan, Minnesota, New York, Ohio, Oregon, Rhode Island, Vermont, the Texas Children's Health Plan, and the Hospital for Sick Children (HSC) Health Care System in Washington, DC. Each of these 12 sites was recognized as having extensive experience in building quality systems of care for CYSHCN and developing innovative models of care and quality monitoring for children.

AMCHP reviewed information from secondary documents available online and corresponded by e-mail or telephone with Title V, Medicaid, and/or health-plan contacts in each of the 12 selected sites to determine whether the states had developed specific standards for either a statewide system of care for CYSHCN or standards specific to a payer or program serving these children. Four sites from this latter group were selected for the case studies: Iowa, Michigan, Rhode Island, and the Texas Children's Health Plan serving Houston and Harris County, Texas. Interviews were conducted using a common protocol tailored to each site to capture the following information: 1) development and use of standards, 2) system reforms, 3) standards deemed as essential to the system of care, 4) lessons learned, and 5) plans for the future.

The National Work Group

A national work group comprised of approximately 40 leaders in the field of CYSHCN, health systems, and quality improvement was convened in July and November 2013 to discuss the findings from the draft white paper, identify areas in need of further development, discuss key considerations as they relate to the ACA, and reach consensus on the focus and content of system standards. The system standards developed as part of this project were fully vetted by the national work group members during their meetings and in draft documents that were sent to the members for review.

Why Are System Standards Needed?

National recommendations and efforts to build family-centered, comprehensive, coordinated systems of care for CYSHCN, including development of standards, date back more than three decades. In 1982, Surgeon General C. Everett Koop held a *National Workshop on Children with Handicaps and Their Families*. The goals of that national meeting were to: develop strategies for comprehensive services needed by children with special health care needs, address the challenges and burdens of the families of these children, and stimulate community resources.[10] Recommendations resulting from that meeting included: 1) defining the scope of the problem, 2) developing standards, 3) developing systems of care, 4) improving financing of care, 5) incorporating principles of care into training for health professionals, and 6) supporting research.[11] The subsequent national report charged the federal MCHB/HRSA in collaboration with the American Academy of Pediatrics (AAP), with implementing a Call to Action (See Figure 1).

Since the 1987 Surgeon General's report, efforts to promote comprehensive systems of care for CYSHCN have been significant. Initiatives and activities to standardize the processes used to implement quality and effective health care for CYSHCN were particularly significant in the 1990s through the mid 2000s. Work led by the MCHB/HRSA in partnership with state Title V CYSHCN programs, and efforts by provider groups (e.g., the American Academy of Pediatrics), families, health services researchers, and other stakeholders has led to important frameworks, a standard definition of CYSHCN, a standard screener for identifying this population in population surveys and clinical settings, pediatric purchasing specifications, and performance measures for the Title V MCH Services Block Grant program, to name a few.

In spite of these important efforts, this project found little literature containing a set of nationally endorsed structure and process standards – standard strategies or processes – that could be used to implement such a system. Confirming the literature review findings, key informants indicated that there were not any meaningful *comprehensive* standards for systems of care serving CYSHCN at the national level. Results from the state survey, which were confirmed by the key informant interviews and case studies, found that there are state-level standards for programs and providers serving CYSHCN. However, these standards are either specific to state Title V CYSHCN programs, focused on contracting, or specific to one component of the system such as care coordination or medical home (e.g., the standards developed by the National Committee for Quality Assurance). In addition, some state standards such as the Rhode Island State Medicaid Agency managed care plan specifications specifically require provision of certain services and contain access standards for certain subgroups of CYSHCN (e.g., those eligible for Medicaid because they are receiving Supplemental Security Income, in families receiving adoption assistance, or eligible for the Katie Beckett Waiver for Home and Community-based Services). In summary, key informants were not aware of any comprehensive national or statewide system standards for health care and related systems (e.g., Title V) serving CYSHCN and their families.

Moreover, there is little evidence from the literature or key informant interviews that any type of standards or the existing model pediatric purchasing specifications for CYSHCN have been systematically used by states, organized health care delivery systems, or providers in the delivery of services to CYSHCN. Uptake by state Medicaid agencies, health plans, state Title V programs and others in the health care delivery system appears to be varied at best even though many of these CYSHCN frameworks and resources have existed for many years.

The variability among states and related systems can be attributed to several factors, some of which are long-standing issues and others that are the result of the ACA and other system reforms. First, there are no nationally recognized and agreed on set of standards that states can use to transform systems for CYSHCN. Second, many states are focused on what are deemed as more urgent priorities within the health care delivery system. These competing priorities include implementation of the ACA, significant reforms in Medicaid, shifts toward newer health care delivery models such as managed care and Accountable Care Organizations, and a focus on higher-cost populations such as the elderly and adult disabled. State budget pressures may have attenuated additional efforts toward use of specific standards for CYSHCN. Finally, partnerships between state Title V CYSHCN programs and their counterparts in Medicaid agencies, insurance commissions, and health plans – which can help improve systems of care for children including CYSHCN – vary widely by state.

Figure 1. 1987 Surgeon General's Call for Action: Children and Youth with Special Health Care Needs

The following Call for Action was outlined in a 1987 national report by the Surgeon General of the United States and underscores the importance of systems of care and related standards for children and youth with special health care needs.

"With the collaboration of families, parent coalitions, State agencies, public and private health care providers, community support organizations, and the health care financing sector, we will be able to accomplish our task. Therefore, I am asking:

- **FAMILIES** – to actively participate in caring for their children and to help shape health care policy and programs.
- **STATES** – to implement systems of care which support the strengths and needs of families, to ensure the input of families at all levels of care, and to ensure the adequate preparation of professionals for new collaborative roles.
- **PRIVATE HEALTH CARE PROVIDERS** – to develop systems which meet the needs of families and which encourage their independence, by forging strong linkages between primary, secondary, and tertiary levels of care (physicians' offices, community health services, clinics, community hospitals, health maintenance organizations, children's hospitals, other teaching hospitals).
- **THE HEALTH CARE FINANCING SECTOR** – to ensure that all children with special health care needs have access to quality health care, and that support services are adequately funded to enable families to care for their children in their own homes and communities.

Improving the financing of care must remain a top priority in our commitment to insurance coverage for all. We applaud Medicaid in the public sector and insurers in the private sector for looking for mechanisms to improve and expand their coverage in cost-effective ways. We ask them to continue and strengthen these efforts."

Source: U.S. Department of Health and Human Services, Public Health Service. Surgeon General's Report: Children with Special Health Care Needs, Campaign '87. Available at: http: //profiles.nlm.nih.gov/ps/access/NNBCFP.pdf. Updated June 1987.

What Are the Opportunities and Context for Systems Development?

Three decades ago, one of the concerns in health care systems was the need for sufficient numbers of primary and specialty care providers willing and able to serve children and youth with special health care needs.[12] The vernacular has changed, along with the system, to the need for medical homes that link primary and specialty care in an integrated fashion. So, too, have the health care delivery models changed from fee-for-service models and carve outs to capitated, organized delivery systems primarily in the form of managed care. Today, more than half of all insured children are enrolled in some form of managed care.[13,14] Underscoring this shift to new models of health care delivery for persons with chronic and disabling conditions, the National Committee for Quality Assurance (NCQA) recently produced a white paper outlining a road map for integrating care for persons with Medicare and Medicaid (i.e., dual eligibles).[15]

Managed care may hold promises to improve access and quality of care for enrollees. However, the details of how this system is structured and implemented are important.[16] For example, only 16 of the 36 states with managed care organizations require plans to be accredited. States use a variety of standards to measure network adequacy; many report that Medicaid beneficiaries sometimes face access problems.[17]

National researchers have discussed the need for special language in Medicaid contracts regarding CYSHCN.[18] The diversity of health care needs and the population as a whole underscores areas of priority for the care CYSHCN receive in managed care. Those areas range from identifying the population, to defining the scope of benefits and medical necessity, provider capacity, family-centered care utilizing a medical home model, and the need for a variety of safeguards to ensure that these children have access to quality care.

Shifts are also being seen in other public programs that serve this population of children such as the Title V MCH Services Block Grant. Federal statute requires that states devote at least 30 percent of Title V Block Grant funds to programs serving CYSHCN.[19] With the advent of new health care delivery models and the ACA, many state Title V CYSHCN programs are moving away from their more traditional role of providing direct health care services to the provision of wrap-around services and supports, and some payment for services not covered by Medicaid or private insurance, among other activities. Furthermore, some state Title V CYSHCN programs such as Michigan are assuming new roles in standard setting as the CYSHCN served by their program are moved into managed care arrangements (see the Michigan case study in Appendix B).

Today, states and payers are working together building new care models driven by a desire to both contain costs and incentivize quality improvement. Many states and insurers are working collaboratively to establish models that centralize and coordinate care (e.g., medical home), ensure quality, limit costs, and assign accountability for their performance. However, most of these delivery reforms and the standards associated with them primarily concentrate on a model of care for adults with chronic conditions rather than children. As the nation moves toward near universal health care for individuals under the ACA, the opportunity and need to create a set of uniform processes that result in effective and quality health care systems for CYSHCN becomes even more important.

While policymakers and payers are focused on reducing growth in health care expenditures, children are often forgotten because as a group they are not the high-end users of health care. Even the small group of CYSHCN with complex medical conditions who require intensive and costly health care, comprise only a small portion of total national health care expenditures.[20] As one key informant noted, “There is an opportunity in the ACA for the application of the ACO model to pediatric care but the thinkers behind the ACO model are not considering pediatrics nor are the payers and others looking for advantages in terms of pediatric cost control in the ACO model.“

The emphasis today on prevention and health care cost containment offers an important opportunity to focus on CYSHCN as part of ACA implementation and other health reforms. Many key informants noted the potential short- and long-term savings that could be achieved by a system that ensures access and coordination of needed services to children with chronic and complex conditions and their families. Early and periodic primary and secondary preventive services to all CYSHCN also provides an opportunity to achieve costs savings while improving health outcomes for CYSHCN.

Key Informant Perspectives: How Standards Can Improve the System of Care for CYSHCN

Key informants were asked about strengths and weaknesses in the current system of care for CYSHCN, strategies to improve the system, and the role of standards. Several key themes emerged from the interviews and are highlighted below.

- **Most key informants acknowledged the need for and potential role of standards to strengthen systems of care for CYSHCN.** Most key informants recognized the importance of standards and were supportive of their development and use. Where key informants diverged on this point was in the areas of: the role of health outcomes and quality improvement in guiding standards development, the fiscal realities faced by health plans and insurers wherein managing the care of higher cost users is a greater priority than adopting standards for CYSHCN, and competing health reform priorities in state Medicaid agencies and health plans.
- **CYSHCN need to be considered in current health service delivery reforms in states.** Key informants uniformly praised the ACA for those provisions that are especially significant for CYSHCN including ending denials of care for preexisting conditions and lifetime caps in private insurance and expanding dependent care coverage to age 26. However, they underscored the need to focus on systems of care for CYSHCN in current system reforms and to put related issues "back on the table."
- **System standards should promote and foster systems integration within health care delivery systems and other child-serving systems. Nearly all of the key informants mentioned the important role standards can play in promoting integration among the many systems that serve CYSHCN.** They emphasized the need for standards to ensure interagency coordination and integration of services among health care, state Title V CYSHCN programs, Medicaid, CHIP, child mental health service providers, health plans, oral health providers, Early Intervention/Part C, school systems, child welfare agencies, family-to-family health information and advocacy organizations, and other community organizations serving CYSHCN and their families. Integration between primary care and mental health services was viewed as extremely important.
- **Standards should build on existing national frameworks for CYSHCN.** The MCHB six core outcomes for CYSHCN are widely recognized and used by state Title V CYSHCN programs, provider groups, health services researchers and others. Most key informants recommended that national standards build on this framework but drill down to the specific *process* and *structural* components necessary to achieve each of these outcomes. Additionally, key informants recommended that the system components be expanded to include other areas such as cultural competence and those issues pertinent to health care service delivery systems. The exception to this finding was noted by health plan and Medicaid agency representatives who were either unaware of the MCHB framework or supportive but acknowledged that they are directed by other priorities for systems development such as health plan certification requirements.
- **Standards for CYSHCN should be aligned with existing adult health care standards.** Key informants stressed the importance of aligning system standards with related efforts to help ensure uptake and use by states (e.g., Title V, Medicaid), health plans and others. Key informants noted that several existing standards for the adult population offer models for standards for CYSHCN, including the NCQA Patient-Centered Medical Home accreditation standards and the Centers for Medicare and Medicaid Services (CMS) Standards of Care for Special Needs Plans serving adults with chronic disease and Medicare/Medicaid dual eligibles (also developed by the NCQA). Although these standards are not focused on children, many health plans are comfortable working with them and they address system issues that are not unique to the adult patient population. In the words of one key informant, "If you give health plans a whole new set of standards not tied to existing standards, it will be harder for them to be implemented."
- **Focus standards on the system components rather than condition specific issues.** Standards should focus on core components of the system, rather than specific conditions, and should apply to the range of children included in the MCHB definition of CYSHCN. Domains for the development of standards as identified by key informants include the following:
    - **Care coordination and medical home:** The critical and central role of medical home and care coordination for CYSHCN were noted and affirmed by nearly all key informants. Feedback and referral loops between the child's family, her or his medical home and care coordinator, community-based service delivery systems,

and a team approach that includes the child's medical and behavioral health specialty providers were cited as a core area in need of focus.

- **Access to care:** Many key informants remain concerned about the availability and capacity of primary care and specialty providers able to meet the needs of CYSHCN particularly in a changing health care environment. Many informants stressed the importance of a standard to monitor access to care.
- **Cultural competence:** Cultural competence is very important if the system is going to be responsive to the needs of its users. It is not explicitly listed as a performance goal for CYSHCN in the set of six MCHB goals; however, its value is implicit throughout the six goals.
- **Family-centered care:** Standards should promote family engagement and partnerships in the design, implementation, and monitoring of systems. Key informants stressed that families should play a central role in the processes of identifying needs, planning care, and coordinating care among other areas.
- **Transition:** Standards addressing transition services should focus on structures and processes to help a youth and their family understand their condition, navigate the system, maximize self-management, and ensure coordination and "hand off" between pediatric and adult medical providers.
- **Information technology and safeguards including Electronic Health Records:** The world of information technology is necessary if information transfer and coordination is to be timely and comprehensive. Safeguards must exist to ensure that technology is appropriate and necessary consents are in place.

- **Standards should address identification and screening of CYSHCN and issues of difficult transitions between coverage types.** The lack of a system for early identification of CYSHCN at the time of enrollment was noted by several key informants as a core weakness of the current health care system. Without a system that identifies children and youth who have special needs on entry into a health care delivery system and related systems to track their care and health care status, other key aspects of care such as triaging, care planning, ensuring timely access to needed care, care coordination, and monitoring of care and outcomes cannot occur effectively. Being able to identify CYSHCN as they lose and gain coverage also was mentioned as very important for plans and providers especially as part of insurance exchange development.

- **Efforts to promote quality measurement and improvement to address health outcomes should be considered in the development of standards.** Key informants from diverse perspectives noted the importance of quality improvement efforts, particularly the Triple Aim,[2] as an important consideration in standards development. As with other areas of health reform, they noted that much of this work is focused on the adult population and that existing child-related quality measures are not comprehensive.

[2] Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff. 2008;27(3):759–769.

Experiences from the States: How Title V, Medicaid & Health Care Plans Are Using Standards for Serving CYSHCN

As part of this project, AMCHP identified examples of promising practices in three states and one large child-only Medicaid health plan. Case studies highlight efforts in three states and one large child-only Medicaid health plan. The focus of these case studies is highlighted below. Full case study descriptions can be found in Appendix B.

- **Iowa.** This case study describes how the Iowa Child Health Specialty Clinics (CHSC), which administer the state Title V CYSHCN program, are using newly developed standards to improve the quality of the CHSC system of care, which includes direct clinical services, family support, care coordination, and infrastructure building.
- **Michigan.** This case study describes how Michigan officials worked closely with families and other stakeholders to develop health plan eligibility criteria and contract standards for Medicaid managed care organizations that began enrolling CYSHCN in 2013. The state goal was to safeguard access to services for approximately 20,000 children receiving Medicaid and enrolled in the Michigan Children's Special Health Care Service Program.
- **Rhode Island.** Rhode Island has developed a comprehensive system of care for CYSHCN through collaborative partnerships between the state Title V agency, providers, parent/family advocacy organizations, and the Rhode Island Medicaid program (RIte Care). This case study describes the core components of this system and the ways in which standards for CYSHCN are embedded in state contracts with Medicaid managed care organizations.
- **Texas.** The Texas Children's Health Plan (TCHP), which serves the Houston and Harris County area, features the health plan's care coordination medical home model. This was implemented with providers serving large numbers of CYSHCN, and its innovative leadership in developing a new statewide, integrated system of care to better serve the needs of children on Medicaid and Supplemental Security Income (SSI).

From the case study research, several cross-cutting themes and lessons learned emerged as important considerations for the development of system standards for CYSHCN.

- **Parent and family engagement and partnerships are critically important.** In each of the case study sites, not only have standards been established recognizing families as core team members in care planning for their children, but parents and families of CYSHCN also have been integrally involved as partners in standards development. Leaders in each of the sites emphasized that parents are very aware of the system issues and care needs that deserve attention. As such, their input has been essential in helping state agencies and health plans develop and prioritize standards. Sites are engaging parents of CYSHCN and parent advocacy organizations in formal advisory capacities to provide feedback and essential accountability for the quality of children's experiences and outcomes.
- **A Medical home model, including care coordination, should be a core focus of standards for systems of care serving CYSHCN.** The majority of state leaders in the 12 potential case study sites noted that they are providing expanded training and incentives to help pediatric providers work toward the guidelines of the Center for Medical Home Improvement, Centers for Medicare and Medicaid Services and/or NCQA medical home accreditation standards. Moreover, all four case study sites had developed standards addressing care coordination, care management, parent engagement, collaboration and communication between a child's primary and specialty providers, and referrals to parent supports and community-based resources for the child and family – all of which are key components of a pediatric medical home. Two states (Minnesota and Oregon) have developed their own medical home standards with some important provisions for children. State and health plan officials in other states emphasized the need for improved national standards and process measures specific to pediatric medical homes as well as better standards to define the components of effective care coordination for CYSHCN.
- **Standards ensuring children's access to specialists and continuity of care are high priorities for parents of CYSHCN.** Officials in Rhode Island and Michigan – both of which have many different standards for CYSHCN in their Medicaid managed care contracts – explained that when their state was moving CYSHCN from fee-for-service to Medicaid managed care, provider access was one of the greatest concerns for families. Specifically, families voiced concerns about availability and access to the specialists and services needed by their child. To address these concerns, Rhode Island and Michigan Medicaid officials took very similar

approaches. As a first step, they each worked with the Medicaid providers and health plans in their states to ensure that CYSHCN would have access to an adequate network of specialists to meet their needs. They both built protections into relevant sections of their Medicaid managed care contracts to ensure that CYSHCN would have easy access to specialists and that newly enrolled CYSHCN could initially continue to see their previous providers.

- **Implementation of the Affordable Care Act underscores the need for states to safeguard what is working well while continuing to strengthen systems of care for CYSHCN.** Several of the state interviewees recognized that the ACA and health care reform in their state provided an opportunity to improve access to not only insurance coverage for CYSHCN, but also improve quality of care and health outcomes. Others were concerned that the significant focus by the ACA on improving accountability and quality of care for adults would eclipse the ability to build on progress they had already made in improving coordination of care, access to care and quality of care for CYSHCN. One state director expressed concern that the implementation of state health care delivery system reform could even result in the dissolution of the strong system of care that had been providing care coordination and access to services for CYSHCN in their state.
- **Standards are essential for systems improvement but need to be linked to a comprehensive effort to ultimately ensure quality of care for CYSHCN.** During interviews for the case studies, most respondents pointed out that standards could form the baseline for quality assurance but emphasized that standards alone would not be sufficient to improving quality systems of care for CYSHCN. These individuals suggested that the time was ripe for focusing on purposeful engagement of families in the development and monitoring of standards and as part of the care coordination teams for their children, adequate financing of care, inclusion of key benefits in health care coverage, provider training, and a strong quality monitoring system tied to financial incentives for improvement. In the words of one health plan official, “While important, standards – like those in Medicaid contracts – are not the primary driving force for building a quality system of care for children.”

Guidance for Development and Use of National Standards for Systems of Care Serving CYSHCN

Based on the literature review and findings from the key informant interviews, it was determined that structure and process standards – standards that address core components of the structure and process of an effective system for CYSHCN – would be the focus of the standards synthesis and development. The availability of clinical practice level standards is significant and under the purview of national provider groups, federal agencies and commissions, and other such entities. Quality measures and indicators are also critical. However, they are not the focus of this work at this stage of the project.

Key informants and national work group members provided additional guidance with regard to development and use of national standards for CYSHCN, with the following broad recommendations:

- **Focus on the health and health care delivery system.** While nearly all key informants recognized that CYSHCN are served by multiple systems, they urged the project to focus this work on the health and health care service delivery system in order to focus efforts and best achieve national consensus. Other systems can be incorporated at a later stage.
- **Prioritize standards that are actionable and provide value.** Key informants cautioned against developing a 'laundry list' of standards and strongly recommended focusing on a core set of essential standards. In the words of one key informant, "Standards are needed that can be implemented and bend the cost curve…You can call them 'strategic prioritization opportunities' if needed."
- **Design standards for use by a variety of target audiences.** Key informants want standards that can be used or adapted for use in a variety of formats by the various systems and organizations that serve CYSHCN. These target audiences include but are not limited to state Title V programs, state Medicaid and CHIP agencies, health plans, family/consumer groups, federal agencies, Accountable Care Organizations, provider networks, hospitals, and insurers. Family advocates stressed the need to use language that can be easily interpreted for use by consumers.

With the key informant recommendations in mind and the findings from the literature review and case study work, standards that focus on the structure and process of an effective system of care for CYSHCN were synthesized and in some cases developed. The system components and related system standards that were synthesized from the literature or practice are contained in a separate companion document to this background white paper.

Conclusion

Children and youth with special health care needs are an important population of children for focus as state Title V programs, Medicaid and CHIP programs, health care systems, children's hospitals, and other entities undergo significant transformation as a result of the Affordable Care Act and other health reforms. Standards for systems serving CYSHCN are important and can play an integral role in efforts to improve the experience of care, improve health outcomes, and reduce health care costs. Reaching national consensus among a diverse group of stakeholders on the focus and content of these standards and the core strategies for their implementation can help realize the promise not only of the goals of the ACA but of long-standing recommendations for improving the health and well-being of CYSHCN.

Appendix A: Project Key Informants

NAME	ORGANIZATION
Richard Antonelli	Boston Children's Hospital, Harvard Medical School
Diana Autin	Statewide Parent Advocacy Network (SPAN), New Jersey's Parent Training and Information Center
Christina Bethell	The Child and Adolescent Health Measurement Initiative (CAHMI)
Meg Comeau	The Catalyst Center, Boston University School of Public Health
Carl Cooley	Crotched Mountain Foundation
Alison Croke	Xerox State Healthcare, LLC & Rhode Island Office of Health and Human Services
Sue Dull	Children's Hospital Association (CHA)
Rosemary Feild	Centers for Medicare and Medicaid Services (CMS)
Eileen Forlenza	Colorado Department of Health
Deborah Garneau	Rhode Island Department of Health
Cathy Hess	National Academy for State Health Policy (NASHP)
Charles Homer	National Initiative for Children's Healthcare Quality (NICHQ)
Lynda Honberg	Family Voices
Henry Ireys	Mathematica Policy Research
Laura Kavanagh	Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)
Neva Kaye	National Academy for State Health Policy (NASHP)
Deborah Kilstein	Association for Community Affiliated Plans (ACAP)
Tom Klitzner	Mattel Children's Hospital at the University of California Los Angeles (UCLA), David Geffen School of Medicine at UCLA
Christopher Kus	New York State Department of Health
Marie Mann	Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)
Jeanne McAllister	Indiana University School of Medicine
Margaret McManus	Got Transition/Center for Health Care Transition Improvement &The National Alliance to Advance Adolescent Health
Kathleen Nolan	National Association of Medicaid Directors (NAMD)
Laurie Norris	Centers for Medicare and Medicaid Services (CMS)
Aimee Ossman	Children's Hospital Association (CHA)
Sara Rosenbaum	The George Washington University
Sarah Hudson Scholle	National Committee for Quality Assurance (NCQA)
Colleen Sonosky	District of Columbia, Department of Health Care Finance
Bonnie Strickland	Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)
Fan Tait	American Academy of Pediatrics
Debra Waldron	Iowa Department of Health
Deborah Klein Walker	Abt Associates, Inc.
Kathleen Watters	Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)
Nora Wells	Family Voices

Appendix B: Site Case Studies

IOWA: Using Standards for Improving Systems for CYSHCN Served by Iowa Child Health Specialty Clinics

Child Health Specialty Clinics (CHSC), an organization within the Division of Child and Community Health within the Department of Pediatrics at the University of Iowa Hospitals and Clinics, administers the Iowa Title V Program for children and youth with special health care needs (CYSHCN). CHSC supports 13 regional centers, four of which concentrate on children's behavioral and mental health services. In federal fiscal year 2012, CHSC provided care coordination, family support or gap-filling direct clinical services to approximately 4,200 children ages 0-21 years, and served thousands more through other public health activities throughout the state. CHSC accepts children regardless of income and insurance coverage, who have a chronic condition, are at an increased risk for a chronic condition, and have a need for special services. Chronic conditions can include physical, developmental, behavioral, or emotional issues. Family Navigators (who are parents or primary caregivers of CYSHCN themselves) provide care coordination and family support by engaging and supporting families who may or may not also receive CHSC clinical services. CHSC staff and families of CYSHCN are directly engaged in the planning and evaluation of services for CYSHCN. In addition to direct clinical care and care coordination, CHSC develops partnerships for advocacy and policy development to strengthen the system of care for CYSHCN in Iowa.

Title V Develops Standards and Quality Measurement Tools to Strengthen the CHSC System of Care

In 2010, as part of the Iowa Title V program five-year needs assessment and strategic planning process, the state recognized a need to put greater emphasis on improving the system of care for CYSHCN statewide. To realize this goal, Title V officials decided they could be most effective by first focusing on the system of care provided by CHSC. They also recognized that while the MCHB six core outcome goals for CYSHCN provide a useful broad framework, they would need more specific measurable process standards to assess CHSC strengths and weaknesses and make targeted system improvements.

To this end, the Title V program developed a new Title V State Performance Measure to assess "the degree to which components of a coordinated statewide system of care for CYSHCN are implemented." CHSC then set out to develop priority process standards in each of the four service components supported by the CHSC system of care: direct clinical care, care coordination, family support, and infrastructure building.

> "(Working on the standards)..has brought enthusiasm to our program-- working together toward common goals and assessing progress as a team…This process of self-evaluation with agreed upon standards provides a thread for people located in different geographic areas to work together toward improving the system of care we have developed."
> *Barbara Khal, Iowa Child Health Specialty Clinics*

Iowa Title V leadership recognized that it was critically important that the process standards be developed using a team process that engaged all CHSC staff who work directly with children and families in the program. In the words of Barbara Khal, executive director of CHSC, "We recognized process standards for the system of care would be useless unless we had teams of people who are directly involved determine the critical elements."

Four workgroups were created, with each group focused on one component and comprised of individuals who work most closely in that aspect of the system. Using a participatory process, each group agreed on priority process standards for their respective component, which they called "elements." CHSC then decided on a 0-5 scaled self-assessment rating tool, which each team would use to quantify the degree to which they were implementing the standards of each element. This tool would be used to track performance improvement. In this tool, a score of "0" meant that the "process is not defined or status is unknown." At the highest end of performance, a score of "5" meant that for this element, "process outcomes are predictable; processes are fully embedded in operational systems; and, the process consistently meets the needs and expectations of all families and/or providers."

How Standards are Being Used for the CHSC Program

The process standards and self-assessment tool that CHSC developed have become an integral part of program operations and quality improvement activities. According to the executive director of the Iowa CYSHCN program, the goal in developing these standards "was to ensure that each process would be in place and sustainable." When asked about specific ways that the development of the specific standards have been integrated into their ongoing work and improved the quality of the system serving CYSHCN and their families, CHSC leadership explained that 'in just two years they have seen much progress. For example, the teams now meet monthly to discuss how they can make progress toward fully implementing each process element and

the teams have improved their performance on many of the elements using this team approach. Twice a year, the teams review and update their ratings on each of the standards. In the following months, they focus on improving performance in those areas where they scored most poorly. Through this internal self-assessment process, the teams also identified the need for process standards that cut across the four components, such as the provision of culturally and linguistically competent services; CHSC assigned a staff member to provide training and staff support to all the teams on these topics.

Iowa CHSC leadership notes that the standards also led to unexpected outcomes. For example, the care coordination team developed a tracking log structured on its 11 care coordination standards (see Figure 2.). These data were initially entered into a simple Access database for internal self-assessments. As the University of Iowa Hospital updated its electronic medical record system (called EPIC), the data elements in the tracking log were integrated into EPIC. As a result, CHSC has access to various data points it can use to evaluate the quantity and quality of the care coordination that is provided and make decisions about the quality of care for CYSHCN based on data. As another example, data from the care coordination team has already been used to improve the competency-based training for Family Navigators. A Family Navigator serves on the care coordination work group that analyzes quarterly data. He/She provides feedback to the Family Navigators working directly with families and provides ongoing mentoring where data indicate improvements are needed. This ongoing quarterly feedback allows rapid change and continuous quality improvement. The data that is entered into EPIC is being used to analyze time allocations of care coordination and family support within the clinic visits. This analysis allows for consideration as to whether more time is needed to serve families of children with more complex needs.

CHSC leadership emphasizes that while quality improvement has always been a priority for CHSC, the new standards and self-assessment process have created many positive outcomes, including increasing collaboration between staff across the state to work together to strengthen the system of care for CYSHCN in Iowa.

Lessons Learned and Next Steps

The Iowa Title V program continues to monitor all aspects of implementation of the ACA and its impact on CYSHCN. CHSC will use the program data from the tools developed for this state performance measure, the accompanying data points tracked in EPIC, and family impact data to show the continued importance of integrating public health into the state health care delivery systems. A future project will be to work with the University of Iowa on analysis of financial and quality metrics for delivering comprehensive services for CYSHCN in an integrated system, such as an Accountable Care Organization (ACO) or Integrated Health Home. Additionally, as Iowa implements Section 2703 of the ACA (Medicaid Health Homes), CHSC is part of the leadership team that is developing health homes for children with chronic conditions, including children with serious emotional disturbances.

Figure 2. Iowa Child Health Specialty Clinics, Care Coordination Standards

1. Comprehensive orientation and training for all care coordinators (e.g. CHSC values, confidentiality, cultural competence, family-directed, health literacy, EPIC, tracking log, roles by professional classification, motivational interviewing)
2. Families know they are receiving care coordination, the name of the care coordinator(s), and how to access him/her and a backup
3. Families provide qualitative and quantitative feedback regarding their experiences with care coordination
4. Families determine the level and type of care coordination support they desire
5. Care coordinators provide appropriate resources to match the health literacy level of CYSHCN and their family
6. Care coordination process assesses CYSHCN/family strengths, needs and monitors ongoing progress
7. Care coordinators connect families to comprehensive resources to match their current and emerging needs
8. Care coordinator(s) assist CYSHCN/family in developing self-advocacy skills
9. Crisis/Emergency plans are in place for children, youth, and families served (as needed)
10. Transition planning for CYSHCN begins on or before 14 years of age
11. Reimbursement mechanisms for care coordination are in place

Appendix B: Site Case Studies *continued*

MICHIGAN: Medicaid Managed Care Standards for CYSHCN

Established in 1927, the Michigan Children's Special Health Care Services program (CSHCS) is a statewide program administered by the Michigan Department of Community Health (MDCH). CSHCS is designed to help families of children who have a severe and chronic medical condition by providing: 1) care coordination through a local health department and 2) payment for specialty services that are not covered by the child's health insurance plan. The program serves approximately 30,000 children, of whom approximately 20,000 have Medicaid insurance.

CSHCS Medical Consultants determine a child's eligibility for CSHCS benefits based on a physician's referral and diagnosis. Children are eligible for CSHCS based on their diagnosis, the severity and chronicity of their condition, and their specialty care needs. Income or insurance coverage is not a factor in eligibility as the program is designed to fill the gaps in services that children need but their families cannot afford because they are either uninsured or underinsured. Once a child is enrolled in CSHCS, the program covers a broad array of specialty services related to the qualifying diagnosis that are authorized by their child's sub-specialty physician, but which their child's insurance (if insured) does not cover, including, but not limited to: ancillary medical therapies and services, home visiting by a skilled nurse, respite care, hospice care, and durable medical equipment and supplies. Primary care, well child care, and mental health services are major services not covered by the CSHCS program.

How CSHCS Participants Were Transitioned into Medicaid Managed Care

In May 2011, the Michigan legislature called for MDCH to develop a plan to transition all Medicaid-eligible CSHCS participants into Medicaid managed care plans (called Medicaid Health Plans or MHPs). State leaders, however, recognized potential benefits to the CYSHCN system of care, including:

- Organized approach to primary care as part of a system of medical care
- Addition of health plan case management leading to enhanced care coordination for all medical care including specialty, primary, and all other covered services
- Ability for quality monitoring, and a concomitant enhancement to the quality of care received
- Access to outpatient mental health services
- Increased access to non-emergency transportation services

Recognizing that an extensive planning and implementation process would be needed to transition this population into managed care, the state legislature and the administration concurred that the integration of the CSHCS population into managed care could not take place until State Fiscal Year 2013.

In 2012, MDCH launched atheir needs assessment and planning process as they had done in earlier years to transition other populations into Medicaid managed care pursuant to the legislature's request. However, according to Michigan's Title V CYSHCN program, this transition was "the most complex of any the state had experienced" and required "thousands of hours of work." The Department began by convening an internal work group comprised of 25 staff from CSHCS and the Medical Services Administration and key experts from the Michigan State University Institute for Healthcare Studies and Maximus, the private enrollment broker for Medicaid in Michigan. This workgroup met monthly with additional meetings for subgroups addressing topics such as data, systems, and coordination. MDCH also enlisted the input of outside stakeholders including the MHPs, providers, and families. The health plans were engaged through regularly scheduled monthly operational meetings that MDCH holds with the Medicaid Health Plans (MHPs). These meetings provided an opportunity to provide input on the infrastructure necessary to successfully serve this population. Separate meetings were held with health care providers, the three largest children's hospitals in the state, and other providers that work closely with the CSHCS program. MDCH also made a concerted effort to seek out family participation and address their concerns throughout the planning process in various ways, including through the CSHCS Advisory Committee, the parent staff who work in the CSHCS program and a series of focus groups conducted with parents around the state.

[3] Children with a wide range of chronic medical conditions requiring specialty care are eligible for CYSHCN, though the program does not include children whose primary diagnosis is a behavioral condition or developmental disability. Additionally, severity is always taken into account in determining eligibility. For example, while children with chronic asthma can be eligible for CSHCS those whose care can be provided by a primary care physician are generally not eligible for CSHCS.

Figure 3. Key Managed Care Contracting Specifications for Enrollees in the Michigan Children's Special Health Care Services Program

- **Network adequacy and accessibility.** The health plan networks must include pediatric subspecialists, children's hospitals, pediatric regional centers, and ancillary providers that provide services to CSHCS enrollees and the MHP "must maintain a network of qualified providers in sufficient numbers and locations within the counties in the service area to provide required access to covered services."
- **Continuity of care.** MHPs must allow CSHCS enrollees to continue to use the primary and specialty providers they have had established relationships with at the time of enrollment, whether or not they are in their networks. MHPs also must pay for provision of ancillary provider services and medical supplies under "prior authorization" agreements that were in place when the child was in fee for service Medicaid (for the duration of the prior authorization).
- **Assignment of a primary care physician (PCP).** PCPs assigned to these children must attest to their experience and ability to serve this population. In addition, MHPs must allow families to choose a specialist to serve as the CSHCS enrollee's PCP, assuming the specialist is willing and able to provide all of the services required of the PCP.
- **Transportation services.** While past Medicaid managed care contracts included a requirement for transportation assistance, the revised contracts clarify that MHPs must, when needed, provide transportation to all covered services.
- **Special grievance and appeal process.** MHPs must maintain a separate system for addressing grievances and appeals for this population with a pediatric specialist involved in the reviews. Additionally, the plans must track and report separately on the grievances and appeals by families of CSHCS enrollees.
- **Care coordination.** Historically, local health departments have helped families enrolled in the CSHCS program develop a plan of care and access the services they need. With the movement of CSHCS children into managed care, the new contracts require each plan to have care managers who specialize in working with children with complex medical needs. At the same time, the plans must enter into formal coordination agreements with their local health departments to prevent duplication of effort and ensure coordinated care for each CSHCS enrollee.
- **Family engagement.** Contract language encourages MHPs to develop forums for discussion between the CSHCS enrollees, their families, and themselves. While the contract language does not specify the format for family engagement, it is suggested that families can be involved through advisory groups, periodic surveys, focus groups, and other venues. Several best practices have emerged already for family engagement, including the engagement of families as ombudsmen for parents of CYSHCN and creation of plan-level parent advisory committees.
- **Outreach and assistance for CSHCS enrollees and their families.** MHPs are required to have a member service telephone line with personnel trained to work with this population and a Web portal with information for CSHCS enrollees. Along with these contract standards, MDCH worked closely with the enrollment brokers and MHPs to assure they would conduct "targeted outreach and education to CSHCS enrollees."
- **Quality measurement.** To enable the MHPs and MDCH to monitor the quality of care provided to the CSHCS population, plans are now required to track quality measures separately for the CSHCS population, including information from HEDIS data sets and the Children with Chronic Conditions (CCC) - CAHPS consumer satisfaction survey.

Appendix B: Site Case Studies *continued*

Michigan Establishes Standards to Protect Continuity of Care, Ensure Access and Quality, and Promote Coordination of Care for CYSHCN in Medicaid Managed Care

Based on input from the various stakeholder groups, the workgroup identified areas where safeguards were needed to ensure the plans would protect access and promote quality of care for current and future CSHCS enrollees. As described below, to prepare the MHPs for serving this population, MDCH developed two kinds of safeguards: 1) initial core competency standards that determined whether the plans would be able to serve the population and 2) very specific managed care contract specifications.

Core Competency Standards

In spring 2012, MDCH developed Core Competencies as guidelines for health plans to evaluate their capacity to serve the CSHCS population. The competencies addressed the following areas: access, network adequacy, referral processing, performance monitoring, grievance/appeals, prior authorization, family involvement, and overall plan performance. MDCH then asked the MHPs to submit documentation to demonstrate their ability to meet these competencies with examples of how they would meet them. Twelve MHPs were deemed eligible and began enrolling CSHCS participants on Oct. 1, 2012.

Managed Care Contract Specifications

Recognizing the strength of contract language as a tool to direct and shape MHP policies and practices, MDCH also revised the contracts with the MHPs. Key provisions in the new contract language are summarized below.

Plans for Monitoring Plan Performance

Several important processes have been put in place to ensure that MHP performance can be assessed and improved in the early implementation stage and on an ongoing basis, including engaging families in the process, conducting in-depth performance site reviews, and monitoring changes in parent satisfaction.

In an interview with Lonnie Barnett, the Michigan CYSHCN program director, he emphasized the important role that families and providers have historically played in ensuring quality of care for CYSHCN in Michigan, and the important role they will continue to play. “MDCH has made a commitment to involve families of CYSHCN throughout the process of planning, implementing and monitoring plan performance.”

To this end, MDCH will establish a new advisory group to provide feedback on how the managed care plans are serving the CSHCS population. This stakeholder group will include representatives from the state CYSHCN program, local health departments, at least five parents of CSHCS enrollees, the managed care division of MDCH, children’s hospitals, providers of durable medical equipment, prosthetics, and orthotics, and others.

In this first year of integration of the CSHCS population, MDCH staff also will conduct an intensive review of the MHPs performance specific to their implementation of some of the new contract requirements and a follow-up on their ability to perform the Core Competencies. MDCH documents indicate that focus areas for review will include: network adequacy; contracts with specialty providers and institutions; the prior authorization process; grievance and appeals processes and the rate and type of grievances and appeals for CSHCS enrollees; the ability of the IT system to track the CSHCS population and generate measures of utilization, access and quality of care for them; the existence of practice guidelines for conditions of CSHCS enrollees (e.g. Type I diabetes, asthma, cerebral palsy, sickle cell disease); mechanisms in place to monitor referral processing time and results; and coordination of medical and behavioral health services. MDCH also plans to use quantitative measures to monitor and promote the quality of care children in CSHCS receive. This will include reviewing the results of the CCC-CAHPS 2012 and 2014 surveys to compare changes in parent satisfaction between the fee-for-service CSHCS environment (2012) and managed care (2014). MDCH also is exploring the development of CSHCS-specific performance measures in addition to the measures already monitored through the existing tools.

> **“Do not rush through the process. Think through what the priorities are and take the time needed. Our planning process required a full 18 months. And, all parties must recognize that transitioning CYSHCN into managed care requires a special process and approach.“**
>
> *Lonnie Barnett, Michigan Department of Community Health*

> **"Effective communication between the state agency, families, MHPs, children's hospitals, local health departments, and other providers is the key to the success of our work in Michigan to date."**
> *Lonnie Barnett, Michigan Department of Community Health*

Lessons Learned

At the time of this publication, enrollment of the CSHCS population into MHPs had just neared completion. While it is too early for MDCH to assess the impact of the standards on access and quality of care for CYSHCN, Mr. Barnett stressed that taking time for planning, obtaining commitments from the health plans who might participate, and engaging key stakeholders in the process are key elements of the process and perhaps just as important as the individual contract standards developed throughout this process.

Appendix B: Site Case Studies *continued*

RHODE ISLAND: Comprehensive Systems Building for CYSHCN

State officials, family advocates and health care providers in Rhode Island share a long history of working together to build a statewide integrated system of care for CYSHCN. This collaborative effort was spearheaded in the late 1990s when the Rhode Island Executive Office of Health and Human Services (EOHHS) and Title V agency and parents of CYSHCN convened the *Leadership Roundtable for Children with Special Health Care Needs*. The *Leadership Roundtable*, which met routinely for more than five years, included representatives from the Title V CYSHCN program, Medicaid agency, the Rhode Island Parent Information Network (RIPIN), Family Voices, the Rhode Island Chapter of the American Academy of Pediatrics, Rhode Island children's hospital, health providers, Medicaid managed care agencies, community health centers and others who work with CYSHCN in the state.

Based on the needs expressed by families of CYSHCN and input from the various stakeholders on the *Leadership Roundtable*, Rhode Island has put in place the following statewide programs and initiatives for CYSHCN:

- The Comprehensive Evaluation, Diagnostic, Assessment, Referral, Reevaluation (CEDARR) Centers
- The Pediatric Practice Enhancement Program (PPEP)
- Inclusion of CYSHCN in Medicaid managed care (RIte Care)

Although their funding and administrative structures are separate, these three initiatives work together as complementary and integral components of the system of care for CYSHCN in Rhode Island.

The CEDARR Family Centers
CEDARR Family Centers were the first of these three initiatives. They were developed for CYSHCN on Medicaid to provide a one-stop location for children to receive screening, diagnoses, education, family supports, and referrals to other Medicaid services including clinical (e.g., medical, behavioral health) and nonclinical (e.g., education, substance abuse and juvenile justice, and home based services such as personal assistance and respite care) services. Center staff develop plans to coordinate care and act as the child's health home.

> "In developing the RIte Care contract language, we sought to take into consideration all that families had taught us over the years."
> *Rhode Island Medicaid Official*

The Pediatric Provider Enhancement Program (PPEP)
PPEP was developed with a focus on improving the capability of pediatric practices to provide coordinated care for CYSHCN by providing needed information and supports to the children and families they see (including families with private health insurance or Medicaid). The program is primarily funded by the participating practices with some contributions from state Title V agency, Medicaid and private insurance reimbursement. It is administered by the Rhode Island Parent Information Network (RIPIN), which trains and places parents of CYSHCN to work on-site at 30 primary and specialty pediatric practices throughout the state. The parents are trained consultants who offer on-site information and supports to the families of CYSHCN to help them coordinate the care their children need, link them with community resources, and navigate the health care system and other services (including education, social services, and housing) that their child needs.

Inclusion of CYSHCN in Medicaid Managed Care Program (RIte Care)
In 1994, when Rhode Island implemented a Medicaid managed care program (RIte Care) for families and children, CYSHCN were carved out and remained in Medicaid with service coverage on a fee-for-service basis. However, in recognition of the need to improve access to care and help families manage the care their children need, beginning in 2003 CYSHCN were gradually included in one of the two state RIte Care managed care plans. First, in 2001, the Rhode Island EOHHS began enrolling children in substitute care arrangements (i.e., foster care) into one RIte Care health plan on a voluntary basis. Next, in 2003 Rhode Island EOHHS offered enrollment in managed care as an option to children in the following Medicaid coverage groups: SSI, adoption subsidy, and children receiving Medicaid through the Katie Beckett provision. Then, beginning in 2008 through 2010, Rhode Island EOHHS required all children in these coverage groups to enroll in a RIte Care health plan.

[4] As of fall 2011, under the section 2703 federal Medicaid option, Rhode Island DHS designated the CEDARR Family Centers as Medicaid "Health Homes" for children and youth with disabilities and chronic conditions.

[5] For more information on the PPEP program see the AMCHP Innovation Station. Also of note is the fact that In February 2013, building on its success in helping families with CYSHCN to access needed services through the PPEP program, RIPIN was awarded federal funding from the Affordable Care Act to set up a "consumer assistance program" to help Rhode Islanders understand and access health insurance coverage.

At the same time that RIte Care was expanded to include CYSHCN, Rhode Island EOHHS was working with families to understand what was needed to ensure quality of care for CYSHCN and with the health plans to ensure they could adequately meet the level and complexity of these children's needs for health care and related services. In addition, Rhode Island EPHHS focused on clarifying the benefits that plans must provide in-network or out-of-network and reinforcing the federal Early Periodic Screening, Diagnosis rules, the contracts included specific language designed to ensure timely access to and quality of care for CYSHCN, promote care coordination, and incorporate the input of parents in the development of each child's care plan.

The key RIte Care contract specifications for CYSHCN fall into four general categories:

- Access to needed pediatric specialty care
- Access to comprehensive behavioral health services for children
- Timely, appropriate, and ongoing needs identification, case management and care planning
- Care coordination between medical providers, medical and behavioral providers, and across systems serving CYSHCN

Figure 4 highlights selected Rite Care contract provisions in each of these areas.

Lessons Learned

When asked about the impact of the systems and standards that have been put in place for CYSHCN in Rhode Island, state officials report that there have been significant gains in access to needed health services and reductions in emergency care and hospitalization for CYSHCN as a result of the PPEP, CEDARR, and the move to Medicaid managed care for CSCHN. A 2012 report by Rhode Island Kids Count confirms this perception based on parent feedback. The report

> "In developing the Rite Care contract language we sought to take into consideration all that families had taught us over the years."
> *Rhode Island Medicaid Official*

states that parents of CYSHCN in Rhode Island have reported "improved access to specialists, behavioral health and nutrition counseling, oral health services, therapeutic child care, and parent support services."

Despite the advancements and successes Rhode Island has had in developing a model system of care for CYSHCN, gaps and challenges still exist for many families. EOHHS officials highlighted the need for better coordination of medical and behavioral health services and improvements in how care is coordinated between managed care organizations (MCOs) and community systems of care and how MCO care managers work with CYSHCN and their families. Other state officials noted that despite the existence of RIte Care contract specifications in these areas today, coordination of care for families and communication across different points of the system (e.g. clinical and non-clinical) is lacking – particularly between the various systems and the child's medical home.

[6] The Medical Home Index (MHI) is a validated self-assessment and classification tool designed to translate the broad indicators defining the medical home (accessible, family-centered, comprehensive, coordinated, etc.) into observable, tangible behaviors and processes of care within any office setting. It is a way of measuring and quantifying the "medical homeness" of a practice.

[7] Examples of quality improvement projects that the pilot sites selected and successfully embedded in their processes of care included: 1) increase the use of the Children with Special Health Care Needs Screener to identify children with chronic conditions and special needs; 2) routinize use of an asthma action plan will ensure the plan is explained to the child and family, including training on inhaler use; and 3) screening for nutrition and activity counseling during a well-child visit.

Appendix B: Site Case Studies *continued*

Figure 4. Key Standards for CYSHCN in Rhode Island Medicaid Managed Care (RIte Care) Contracts

Access to Needed Pediatric Specialty Care

- Plans must provide access to pediatric specialists in "sufficient numbers and locations to ensure specialty services can be made available in a timely manner"
- CYSHCN can choose a pediatric specialist to be their Primary Care Provider (PCP)
- CYSHCN who require ongoing treatment or regular care monitoring by a specialist must be allowed direct access to a specialist, without prior authorization
- To ensure continuity of care, plans must allow newly enrolled CYSHCN to continue seeing out-of-network providers, including specialists, for up to six months after enrollment

Access to Comprehensive Behavioral Health Services for Children

- Plans must have the "full continuum" of services for children's behavioral health needs in-network, including acute services in a 24-hour hour clinical setting, intermediate services, and less intensive outpatient services and community support services

Identification of Needs and Care Management

- Plans must conduct outreach to newly enrolled CYSHCN and within 45 days of enrollment conduct an "initial health screen" to determine the level of care management needs
- Based on the results of the initial health screen, a care manager specialist for CYSHCN must develop a care plan for the child. For children with simpler needs, this can be a short-term care plan. For CYSHCN with more complex care and support needs, the care manager must develop an "intensive care plan" that is reviewed and updated at least every six months
- Plans must be developed in collaboration with the child's parents, guardians, or caregivers, and his/her PCP
- Care plans must be updated for CYSHCN at least every six months
- Plans must make care managers available to CYSHCN and their families throughout their enrollment in the health plan "as such needs arise"

Care Coordination

- Plans must require communication and collaboration and promote timely exchange of information between the child's PCP and specialist who is coordinating the child's care
- Plans must ensure coordination between in-plan medical services and behavioral health services
- Plans must have policies and procedures for referring children to and coordinating with many social and public health programs including services specified in a child's Individualized Education Plan (IEP), the Early Intervention Program, the CEDARR Centers, and home and community-based service providers

Appendix B: Site Case Studies *continued*

RHODE ISLAND *continued*

Recommendations for Other States Developing Systems of Care for CYSHCN

When Rhode Island Title V and Medicaid officials were asked what they learned from their experiences that would be useful to recommend to others states in developing standards to enhance their systems of care, they emphasized the following factors as fundamental to their successes.

- **Cooperation and partnerships between Title V and Medicaid.** Joint program planning and collaborative work relationships between the Rhode Island Medicaid and Title V CYSHCN program were essential. State officials said that by working together and linking funding across programs, the system is now stronger since they have a shared understanding of the needs of CYSHCN and have made a commitment to work together to address them.
- **Close working relationships with health plans.** Rhode Island state officials stressed the importance of working in a collaborative fashion with health plans when CYSHCN are first moved into managed care as well as after contract award to address systemic problems that may be identified from parent feedback or through the routine plan performance monitoring process.
- **Family supports, engagement, and partnering.** Rhode Island EOHHS officials emphasized how important the inclusion of supports for families is when designing managed care plans for CYSHCN. In the words of one state official, "The child has no greater asset than a parent of family that is supported and enabled to help that child. If we don't support and enable parents and families to help their child, then the child will have less of a chance to do well."

State officials urged the engagement of families as partners in systems development. They noted the importance of building in standards to ensure that parents are integrally involved in the development of their child's care plan. Even more important, they urged states to listen to and engage families in the design and implementation of policies and programs. They also recommended putting in place systematic methods to ensure a "continuous feedback loop from parents" to inform state officials about problems as they arise and how the effectiveness of the system could be improved.

Appendix B: Site Case Studies *continued*

TEXAS: Systems Building the Texas Children's Health Plan Experience

Texas Children's Health Plan (TCHP), a nonprofit provider-owned plan, is the third largest Medicaid/CHIP MCO in Texas. The plan serves approximately 344,700 children in Jefferson county, Houston/Harris county, and surrounding counties, including an estimated 65,000 children who have mild to moderate special health care needs. This number includes approximately 24,000 children who have a diagnosis of asthma, 11,000 who have attention deficit hyperactivity disorder in need of chronic disease management and 700 who have diabetes.

For several years, TCHP has been developing new processes to achieve what is widely known as the Triple Aim: quality care, improved outcomes for CYSHCN and their families, and reduced costs – particularly the high costs of preventable hospitalizations and readmissions. As a provider-owned MCO, leaders of TCHP recognize that several strategies are necessary to achieve these aims. Specifically, such strategies must:

1. Include excellent primary care and specialty providers in the network
2. Support providers who want to serve these children, improving the quality of care delivered by becoming pediatric medical homes

3. Address barriers to accessing care, especially by reducing no-shows, and promoting use of preventive care and chronic care visits
4. Help providers identify CYSHCN and access data that would reveal whether families had filled needed prescriptions and been able to follow-through with the PCP referrals for other needed care and monitoring (such as laboratory tests and specialty care)

Medical Home Pilots

To this end, in 2011, TCHP implemented a multipronged six-month medical home pilot project, which included providing each participating practice a registry with information on claims and prescriptions filled for each CYSHCN in their panel; placing a nurse care manager in their office; and engaging the practice staff in a quality improvement process. The pilot had two key objectives: 1) help primary care practices to identify CYSHCN who require close management, bringing them in for face-to-face office visits that would allow providers to identify barriers to care, develop a collaborative care plan, and conduct follow-up to ensure they could access the care and resources they needed; and 2) facilitate collaboration and communication within and among participating practices so that they could provide family-centered care by embedding care coordination as an essential element for managing the care of and providing services to CYSHCN.

Six large pediatric practices were selected for the pilot; a part-time nurse manager was assigned to each. The following section summarizes the core components of the pilot – population management, individualized care coordination, and quality improvement at the practice level.

- **Population Management.** TCHP quickly realized that it would not be enough to manage individual patients: It needed processes to manage an entire population. To that end, it tried several approaches, such as weekly analyses of its centralized claims registries and pharmacy fill data on TCHP enrollees at each pilot site. Using this information, the nurse case manager worked with the scheduler in each office to make appropriate follow-up appointments for children.
- **Individualized Care Coordination.** To be effective, population management must be coupled with care coordination for individual children. To this end, nurse case managers conducted a comprehensive assessment of each CYSHCN *before* the clinical visit. The nurse case manager would meet with each child

and family to conduct a developmental screening, identify barriers to care, and assess the strengths, needs, and desired goals of the family. Nurse case managers shared the findings with the PCP; following the actual clinical visit, they would work with the provider and the family to create an individualized care plan. TCHP set specific standards for these care plans to ensure that they included components essential to supporting children and families. These components included developing action steps; creating transition plans (for teenagers); making referrals to community organizations and resources and other TCHP staff; and developing plans to ensure continued communication among the PCP, other specialists, and the family. Nurse case managers provided ongoing support to families. In addition to making sure that the care plan was followed, they served as an advocate to children and families, helping them to identify and obtain other services, including social services and educational resources.

- **Quality Improvement at the Practice Level.** Quality improvement was an essential element of the program. At the start of the project, the nurse case manager distributed the pediatric Medical Home Index tool to all practice staff. This tool encompasses six domains: organizational capacity, chronic condition management, care coordination, community outreach, data management, and quality improvement. Once the tool was completed, the nurse case manager shared findings with practice staff, and helped them collectively to identify their strengths and weaknesses and work on a quality improvement project of their choosing.

Pilot Study Results

When the six-month medical home pilot period was completed, TCHP offered to continue the embedded care coordination, provision of data on CYSHCN, and other quality improvement supports to the six practices. Only one of the six practices declined the offer. Among the participating sites, all implemented successful quality improvement projects. Comparison of pre and post pilot data reveals impressive results such as: improved Medical Home Index mean scores, lower hospital admission rates (in four sites the reduction was statistically significant), and a statistically significant decrease in TCHP monthly claims/costs per member.

Process evaluation results also proved to be informative, and helped TCHP in its design of additional broad-based systems reforms for CYSHCN. A survey of the pilot site staff found overwhelming agreement that the medical home quality improvement project helped with overall office communication, and that having the case manager embedded in the office setting helped not only to enhance patient care, but to improve the office environment.

At the same time, focus group discussions with nurse care managers provided important insights and suggestions for further study and change. For example, nurse care managers noted that lack of electronic records and other IT system gaps limit the ability of each practice to internally identify and track children's care plans and their receipt of services, as well as their ready access to the TCHP patient registry and other data systems. Input from the focus groups also revealed the need to develop a more coordinated follow-up system for families who need it.

Proposed State Medicaid Pilot to Coordinate Health Care Delivery System for SSI Children

In 2012-2013, TCHP, working with its partners in Medicaid managed care plans across the state (called the STAR program in Texas), developed a new "managed care health organization" framework for serving children who receive SSI and Medicaid (called STAR in Texas). The lead authors of this Children's SSI STAR Framework are Dr. Giardino, the TCHP Chief Medical Officer and Christopher Born, the president of TCHP. The framework was designed based on lessons learned from past systems improvements, including the medical home pilots, and responded to the opportunity presented by the Affordable Care Act for states to create new models of patient-centered, high-quality, cost-effective and comprehensive health care.

The structure of this new statewide network for SSI children would unite all the Medicaid networks that had been serving these children (managed care and fee-for-service) under an umbrella STAR MCO product. The new product would include three tiers of PCP provider networks ("regular," "select CYSHCN PCP," and "premier CYSHCN PCP"), and also would be reimbursed at different levels. The draft proposes integrating specialty physical health and behavioral health into the statewide network and to work with academic centers that care for complex CYSHCN to provide just-in-time technical assistance and support to community providers who want to care for CYSHCN but lack the expertise and confidence to care for complex children. The core of this framework is its emphasis on family- and child-centered care. The network improvements also would be based on standards of quality that focus on family

Appendix B: Site Case Studies *continued*

partnerships, care coordination, and quality monitoring and improvement. Key elements of the framework include:

- **Emphasis on Family Partnerships.** The family and child are at the heart of the system of care: patient-centered care and family engagement are central. The authors explain that parents (or other caregivers) would be integrally involved in planning and care delivery "in order to have substantive input into the way their loved ones will be cared for and empowered to oversee their care to ensure that the children and their families obtain indicated care when and where they need it and that the care is delivered in a culturally and linguistically appropriate manner."
- **Care Coordination.** Care coordination – of clinical care, social services, and educational resources – is the glue of the system. The framework recommends embedding a care coordination team at each practice to serve large numbers of beneficiaries. Responding to lessons learned from the medical home project, the authors propose that the care coordination team at sites serving large number of CYSHCN would include not only a nurse case manager, but a navigator, a parent consultant, a health educator, and an outreach worker. For smaller practices, those teams would be available to serve CYSHCN but not work on-site.

Next Steps

In April 2013, the Texas State Senate passed Senate Bill 7, which would establish a statewide STAR Kids program. The bill is now going through the legislative process in the Texas House of Representatives. Beginning Sept. 1, 2015, most children and young adults under the age of 21 who receive SSI Medicaid or home and community-based waiver services will receive some or all of their Medicaid services through a program called STAR Kids. STAR Kids will be a Medicaid managed care model designed specifically for children and young adults with special needs. Children enrolled in STAR Kids will receive comprehensive service coordination. Children and youth who are enrolled in the Medically Dependent Children Program will get all of their services through STAR Kids. Those who receive services through the Youth Empowerment Services (YES) mental health and substance abuse waiver also will be served through STAR Kids. Children and youth who receive services through other home and community-based programs administered through the Department of Aging and Disability Services (DADS) will continue to receive their long-term services and supports through that program, but their acute care will be provided through STAR Kids. As proposed, the Medically Dependent Children Program will start moving its members into STAR Kids in September 2014. The Deaf Blind Multiple Disabilities (DBMD), Home and Community-based Services (HCS) and Community Living Assistance and Support Services (CLASS) Medicaid waiver services will continue to be available for those who need it, though currently there is a 10-year waiting period for waiver programs. The pilot authorized in Senate Bill 7 bill would result in increased access to services and care coordination at home and in the community. TCHP officials emphasize that this state pilot is aligned with the goals of the Affordable Care Act "by encouraging personal accountability and appropriate utilization of health care services, including alignment of payment incentives with high-quality, cost-effective health care."

Lessons Learned

Commenting on the results of its medical home pilot projects and future efforts to implement system improvements in the quality of care for CYSHCN, TCHP medical director said, "The principles that underscore an ideal patient and family centered medical home have constantly shown an ability to deliver increased quality of care in a cost effective manner. We seek to connect the resources from MCO to the service delivery effort of primary care providers in a way that produces a sustainable care model that will engage the resources to actually deliver on the promise of a medical home for a given child and family."

As TCHP awaits the movement of the STAR Kids legislation through the state legislature, it is moving forward with other innovations to improve the quality of care and coordination of care for CYSHCN in the Houston area and statewide in several ways. First, TCHP is in the process of establishing its own STAR Kids. In addition, TCHP was awarded an MCHB State Implementation for Systems of Services for CYSHCN grant for three years, partnering and sharing resources with the Texas Title V program, Texas Pediatric Society and Texas Parent To Parent to promote the medical home model and improve the system of services. Most recently, TCHP is engaged in a new quality improvement project to engage noncompliant families and diabetic teens. The "connector" will establish an ongoing relationship with diabetic youth and their family to improve the engagement of youth in their own care to improve health outcomes. While focused on one specific disease group, the project will be another example of how health plan resources complement and strengthen the patient-physician relationship and improve outcomes for CYSHCN.

Endnotes

1. McPherson M, Arango P, Fox H. A new definition of children with special health care needs. *Pediatr*. 1998;102:137-140.
2. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook: 2005–2006.* Rockville, MD: U.S. Department of Health and Human Services, 2008.
3. U.S. Department of Health and Human Services, Public Health Service. Surgeon General's Report: Children with Special Health Care Needs, Campaign '87. Available at: http://profiles.nlm.nih.gov/ps/access/NNBCFP.pdf. Updated June 1987. Accessed Mar. 10, 2013.
4. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook: 2005–2006.* Rockville, MD: U.S. Department of Health and Human Services, 2008.
5. U.S. Department of Health and Human Services. Healthy People 2020 Topics and Objectives. Available at: http://www.healthypeople.gov/2020/topicsobjectives2020/default.aspx. Accessed on Dec. 21, 2013.
6. National Committee for Quality Assurance (NCQA). Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2011. Washington, DC; National Committee for Quality Assurance, 2011.
7. U.S. Department of Health & Human Services, Agency for Healthcare Research and Quality. Children's Health Insurance Program Reauthorization Act (CHIPRA). Available at: http://www.ahrq.gov/policymakers/chipra/index.html#Core2. Updated March 2013. Accessed Mar. 10, 2013.
8. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Performance Measures. Available at: http://mchb.hrsa.gov/training/performance_measures.asp. Accessed Mar. 10, 2013.
9. The George Washington University Center for Health Services Research and Policy. Purchasing specifications related to pediatrics services: A user's guide. Available at: http://sphhs.gwu.edu/departments/healthpolicy/CHPR/newsps/peds-user-guide/Pediatric_Guide.pdf. Updated July 2002. Accessed Mar. 10, 2013.
10. U.S. Department of Health and Human Services, Public Health Service. Surgeon General's Report: Children with Special Health Care Needs, Campaign '87. Available at: http://profiles.nlm.nih.gov/ps/access/NNBCFP.pdf. Updated June 1987. Accessed Mar. 10, 2013.
11. Ibid.
12. U.S. Department of Health and Human Services. Report of the Surgeon General's Workshop on Children with Handicaps and Their Families. Washington, DC: U.S. Department of Health and Human Services; 1982.
13. Ireys HT, Grason HA, Guyer B. Assuring quality of care for children with special needs in managed care organizations: Roles for pediatricians. *Pediatr.* 1996;98(2):178-185.
14. Hughes DC, Luft HS. Managed care and children: An overview. *The Future of Children: Children and Managed Health Care.* 1998:8(2):25-38.
15. National Committee for Quality Assurance. Integrated care for people with Medicare and Medicaid: A roadmap for quality. Available at: http://thescanfoundation.org/sites/thescanfoundation.org/files/ncqa-integrated_care_for_people_medicare_medicaid-3-6-13.pdf. Updated March 2013. Accessed Mar. 10, 2013.
16. Gifford K, Smith V, Snipes D, Paradise J. Kaiser Commission on Medicaid and the Uninsured. A profile of Medicaid Managed Care programs in 2010: Findings from a 50-state survey. Available at: http://kff.org/medicaid/report/a-profile-of-medicaid-managed-care-programs-in-2010-findings-from-a-50-state-survey/. Updated September 2011. Accessed Mar. 10, 2013.
17. Ibid.
18. Fox HB, McManus MA. Maternal and Child Health Policy Research Center. Improving state Medicaid contracts and plan practices for children with special needs. *Future Child*. 1998;8(2):105-118.
19. U.S. Department of Health and Human Services, Health Resources and Services Administration. State MCH-Medicaid coordination: A review of Title V and Title XIX Interagency Agreements, 2nd Edition. Available at: http://mchb.hrsa.gov/pdfs/statemchmedicaid.pdf. Updated 2008. Accessed Mar. 10, 2013.
20. Tobias C, Comeau M, Bachman S, Honberg L. Risk adjustment and other financial protections for children and youth with special health care needs in our evolving health care system. Boston, MA: The Catalyst Center at Boston University School of Public Health, 2012.

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